ESTEEM

Effective Support for Self Help / Mutual Aid Groups

Stage 2 Report

March 2013

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Acknowledgements

We would like to thank the self help / mutual aid groups who gave up their time to take part in this study and for their continuing involvement in the research.

We are very grateful to the practitioners with expertise in supporting self help / mutual aid groups for their contribution to this study.

Finally we would also like to thank the Big Lottery Fund for funding this research.

Project Management Group

The research study is a partnership between Self Help Nottingham, Anglia Ruskin University and The University of Nottingham. The overall management of the project is led by:

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Project Advisory Group

A project advisory group, comprising the project management group and additional representation from the Department of Health, health and social care commissioning, practitioners, academics and self help / mutual aid groups, meets every four months to monitor the progress of the study and advise on issues arising.

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1.1 The aims and objectives of ESTEEM

The ESTEEM study was funded by the Big Lottery Fund with the overall aim to produce evidence-based resources for health and social care practitioners on how they can best support the development of self-help / mutual aid groups[1]. This study started in May 2010 and was carried out three stages in two study locations: Essex and Nottingham. The study objectives involved:

Stage 1	1. To develop a typology of self-help groups
	2. To explore and describe the form, focus, function, achievements and challenges of a sample of self-help groups in Essex and Nottingham
Stage 2	3. To identify the training and support needs of self-help groups during different stages of their development
	4. To describe best practices in the support of self-help groups and for the potential collaboration between self-help groups and health and social care practitioners
Stage 3	5. To develop and disseminate good practice guidance on working with self-help groups to relevant organisations and practices.

The focus of this report is to present the findings from Stage 2 of the study. It draws upon and incorporates the practitioner and group data from Stage 1[2] to highlight similarities and differences in opinions between practitioners and self-help group members. Ethical approval for this stage of the study was granted by the NRES Committee East of England - Cambridge South. Research governance approvals were granted by the relevant NHS Trusts where applicable.

1.2 Methods

The principles of participatory action research (PAR) have informed and guided the study throughout. PAR is defined as, "the study of a social situation carried out by those involved in the situation in order to improve both their practice and the quality of their understanding" (Winter & Munn-Giddings, 2001, p.8). Self-help group members, professionals, commissioners and others came together to plan and review the research at each of its three stages. This approach is valued for the way it helps to bring about research that has a practical impact and relevance. Qualitative research methods were

[1] Although the term 'self help / mutual aid group' is felt to be the most appropriate, as it brings together self-responsibility with the reciprocity among group members that enables individuals to help themselves, for greater readability it is abbreviated throughout the remainder of the report to 'self help group'.
[2] The Stage 1 Interim Report is available at www.selfhelp.org.uk/research

employed to gain an in-depth understanding from both group members' and practitioners' perspectives.

1.2.1 Stage 1

Identifying the Stage 1 study sample

Defining and classifying a self-help group remains a contested area due to the variety in form, function and focus such groups take. However, four characteristics are often described as essential features and it was these characteristics that were used as a guide when identifying groups to participate in this research:

- Members share an experience or problem.
- Members come together for mutual support.
- Members control and own the group.
- Membership is voluntary.

(Wilson, 1994; Elsdon et al 2000).

Self Help Nottingham had a local database of 202 suitable groups for the Nottingham sampling frame, but in Essex researchers had to draw on a range of databases, websites and professional contacts to achieve a sampling frame of 24 groups. The final sample of ten groups in each site was purposively selected to include:

- A range of health and social issues.
- Established and new groups (not more that two years old).
- Affiliated and independent groups.
- Groups run by and for people from Black, Asian and minority ethnic (BAME) communities.

All selected groups agreed to participate except one where members felt they did not need outsider support, although the group coordinator agreed to be interviewed and a further group was successfully invited. Therefore with limited data from one group there was a total sample of 21 groups, which are prefixed by the letter C and numbered 1-21 in the findings.

In total 21 semi-structured interviews of 45-120 minutes with group coordinators and 20 group discussions of 45-90 minutes with members were undertaken. The data was collected in Essex and Nottingham from June 2010 to February 2011. The focus of the interviews explored the groups' purpose, ethos, activities, achievements, challenges and external relationships. Coordinators were identified by their groups and group discussion participants were self-selected. Interviews and discussions were taped and fully transcribed except where groups preferred written notes (n=5).

In addition 12 semi-structured interviews were undertaken with practitioners working with self-help groups, either directly or indirectly. The Project Management and Advisory Group, along with suggestions made by the participating self-help groups,

identified practitioners to interview. These interviews began to explore the practitioners' motivation and experience of working with self-help groups, and the training and support needs of such groups. Interviews were undertaken between February and April 2011, lasting between 45 minutes and two hours and are prefixed by the letter A and numbered 1-12 in the findings.

Data analysis

The interviews and groups discussion were thematically analysed at each study site, following steps outlined by Mason (2002). The two researchers who had collected the data wrote up findings from their own study site. A third researcher brought the analysis together in a draft report which was shared with the participating groups and Project Management Group, and further refined. An overview of the Stage 1 findings are reported elsewhere (ESTEEM 2011).

1.2.2 Stage 2

Identifying the Stage 2 practitioner sample

The purpose of Stage 2 was to build on identifying the training and support needs of self-help groups and to identify best practices for practitioners in the support of these groups. As a result six of the twenty-one Stage 1 groups (three from each study location) were asked to identify up to three practitioners who they felt had supported the group at any stage of their development. The six groups that participated in this second stage were selected on the original sampling criteria, which consisted of:

- A range of health and social issues
- Established and new groups (not more than two years old)
- Affiliated and independent groups
- Groups run by and for people from Black, Asian and minority ethnic (BAME) communities.

As a result of competing family and work commitments none of the four BAME groups from Stage 1 were able to participate in the next stage. Therefore the six groups that participated in Stage 2 were selected on three of the four sampling criterion for inclusion.

A couple of groups in Nottingham struggled to identify more than one practitioner who had supported them, and some practitioners did not respond to our invitation of participation. Therefore, the decision was taken to invite those practitioners who were not directly linked with the study groups. Instead practitioners who were known to be working directly or indirectly with self-help groups in general were purposively invited to participate. Particular attention was taken to capture those practitioners who had links with BAME self-help groups.

In total 14 semi-structured interviews of 30-90 minutes were undertaken with practitioners, equally distributed across the two study sites. Six were directly linked to the

study sample groups, whilst the remaining 8 were known to be working directly or indirectly with self-help groups generally. The data was collected from September 2011 to June 2012 and are prefixed by the letter B and numbered 1-14 in the findings.

Data analysis

The Stage 2 practitioner interviews were firstly thematically analysed independently by the two study site researchers, who then reviewed again the 12 practitioner interviews from Stage 1. Preliminary themes and findings were shared, discussed and developed at a two-day analysis meeting in August 2012 with the research team. These preliminary findings and ideas were shared at a number of consultative workshops with both self-help group members and practitioners. Feedback from these consultations guided the study site researchers in their re-examination of the Stage 1 group data to identify similarities and differences in opinions. Individual reports were written and then shared and discussed with the Project Management team. These reports were integrated and refined by a third freelance researcher who brought the analysis together in one report. Further comments were then made by the Project Management Group in March 2013 and refined.

2. Overview of practitioners and self-help groups

In total twenty-six practitioners with expertise in working with and supporting self-help groups were interviewed across both stages of the study. These practitioners worked in a variety of different settings across the UK with varying levels of involvement and direct experience with self-help groups. Most were located within the voluntary sector, which included representatives from national charities and local community oriented organisations. Table 2.1 below lists the variety of practitioners' job role and sector location.

Table 2.1: Practitioners' job role and sector position

Voluntary sector (n = 14)	**Local Authority (n = 6)**	**NHS (n = 6)**
CVS Engagement officers x 3	Social worker	Specialist nurse
National charities representatives x 7 (Chief executive / Regional manager/ Area manager / Director/ Training and Development manager Service Manager / Coordinator)	Mental health therapist	Clinical lead
Grants manager	Commissioner	Physiotherapist
Health & Social Care Officer	Advice and information officer	Clinical manager
Community development workers x 2	Mental health recovery worker	Community development workers x 2
	Partnership development officer	

The 21 groups that participated in the study focused on a wide range of health and social issues. Broadly these came under three categories of physical health problems; mental health problems; and lastly, social issues such as isolation and discrimination. Table 2.2 below lists the groups within these categories.

Table 2.2: Self help groups' health and social conditions

Physical health (n = 10)	**Mental health (n = 5)**	**Social issues (n = 6)**
Aphasia (1) Arthritis (1) Cancer (2): 1 generic / 1 specific Diabetes (2) Drugs & Alcohol (1) Epilepsy (1) ME (1) Vertigo (1)	Diagnosis specific (2) Gender specific (1) Gender and ethnicity specific (1) General (1)	Chinese men and women (1) Gay men (1) Parents group (autistic children and children with special educational needs) (2) South Asian women (2)

3. Range of practitioner involvement

3.1 Who were the practitioners?

The respondents had a range of interests and levels of involvement, from purely strategic to direct input within the groups. The two groups focused on children received support from a variety of school staff, including teachers, teaching assistants, school nurses and liaison workers and Head Teachers. These groups also had supportive relationships with dyslexia services, special educational needs advisors and other local authority educational specialists.

Many groups received support from health and social care practitioners. Some, such as specialist and community nurses, regularly provided a range of assistance. Many came as speakers including neurological and paediatric consultants, podiatrists, dental workers, nutritionists and pharmacists. Mental health support workers, counsellors, psychiatrists and community mental health teams were involved in different ways.

Just under half the groups (n=8) were affiliated to national charities with a special interest in their health or disability issue and most of these received support from regional or national offices.

Voluntary sector workers were involved with groups in a range of ways and to varying degrees. Self-Help Nottingham provided specialist support that is not available elsewhere. Details of participating practitioners are provided in section one.

3.2 Why were they involved and what was their approach?

Practitioner involvement was motivated by a mix of professional and personal interests. Some saw the groups as a means of consolidating and enhancing the beneficial effects of health and social care services, even believing that groups could save service costs. The practitioners had an interest in encouraging local participation, community empowerment, local networks and social capital. Most spoke of mutual benefit from their involvement.

On the whole practitioners supported groups because it was part of their job role, at an individual or wider organisational level. A few demonstrated a personal commitment by continuing to work with the groups when it was no longer part of their job role or by negotiating continuing contact time when their (health care) job descriptions were revised.

The manner and depth of practitioner involvement depended on numerous factors, the most important of which, not surprisingly, was the extent to which their position enabled this work. For those practitioners without an explicit remit for supporting community-based groups, constraints such as time and the attitude of their employers played a part in how far they were able to work with them. Some voluntary sector practitioners were employed to support all aspects of group development, while others had a more specific focus such as assistance with funding or promoting participation in service consultations.

Health and social care professionals also tended to be involved with particular aspects of groups for example providing information or practical assistance.

Practitioners' professional culture sometimes influenced how they worked. A few believed that they should be closely involved in maintaining appropriate group processes in certain circumstances, generally explained in terms of health or cultural needs such as mental health or for certain ethnic minority groups (discussed below). Others (especially within the community sector) preferred a more responsive approach. It would be misleading to suggest that the lines between these ideas or the professional cultures from which they came were clear-cut. There were marked differences within as well as between the sectors. A few health and social care practitioners, for instance, had personal experience of belonging to a group or for other reasons strongly encouraged a member-led ethos. On the whole, most practitioners favoured a collaborative approach.

> Doing it for people doesn't help them in any way. Do it with them. (B12)

Most stressed the need for groups to be ultimately independent and member-led. They felt that their level of involvement should, as far as possible, reflect the needs of the groups as perceived by the members themselves.

> I also don't sit in on the group…The only times I do is if I'm invited to come and do something specific. And I will do the something specific then leave. (A6)

The groups' ethos, capacity and expectations influenced the nature of practitioner involvement, as the data presented here will show. Group support needs varied during their evolution and with the level of skills, experience and competence of leaders and members. Differences in the culture and health of group members also indicated different needs and approaches to support. Three of the four ethnic minority groups in the study received extensive, continuing support, one from a voluntary sector agency and two from a mix of professionals and volunteers within their own community. Groups that focused on addiction and mental health issues were perceived by some practitioners (and some groups) to require more intervention, particularly with facilitation. There could be tension between the perspectives expressed by those professionals who spoke of the higher needs of these groups, and the views of group members who wanted help but also valued their autonomy.

All these factors influenced whether practitioners worked in an in-depth, 'hands-on' approach or in a more distant but also supportive way. The appropriate approach and balance of practitioner involvement is a recurring theme in this report.

The next section of this report presents greater detail around the approach and activities of practitioners supporting self-help groups. The data shows the complex, sometimes contested nature of this work throughout this section, with more intractable complexities and tensions described in section five.

4. Ways of working

4.1 How did practitioners make contact with groups?

There is little direct data about the most effective ways in which practitioners can approach self-help groups, as it was more common, amongst those groups not begun by professionals, for founder or key members to approach practitioners rather than vice versa.

> I contacted Arthritis Care … an information officer from the central office came and talked about options and I then talked to a regional organiser to get what our choices were. (C3)

Similarly the practitioners from voluntary sector organisations tended to allow groups to make contact with them, explaining that this was more appropriate because some groups might prefer to "keep to themselves"

> I tend to work on a responsive basis…So there's some groups I've actually never met because they don't want me to. (B12)

Health practitioners became aware of and made contact with groups in a number of ways including an introduction from a colleague and being invited to speak at group meetings. One had played a key role in the instigation of the group, through inviting the eventual members to take part in an evaluation project.

4.2 The range of practitioner support

Practitioners participating in this study included those who occasionally visited a group, those regularly involved, often providing practical assistance, and those who took on lead roles in facilitation and coordination for groups who still retained a strong sense of autonomy. There were broadly four areas in which practitioners provided support:

- Organisational development (infrastructure and resources);
- Nurturing members and process (leadership, capacity, participation, dynamics);
- Enhancing and sharing expertise (increasing knowledge and understanding);
- Increasing connections, credibility and influence (promoting profile, voice and understanding within the NHS and local community).

The way in which practitioners approached and worked with the group varied widely. A few speakers and training organisations regarded groups as a paying customer but most practitioners emphasised how their involvement brought mutual benefit for themselves and groups and wider benefits for those affected by the specific health or social issue, local services and the local community (presented in Section 6). This report now considers each area of practitioner support, describing their activities and roles.

4.3 Organisational development: infrastructure and resources

The span of practitioner support

Practitioners' activities to support organisational development included capacity-building, training and advising on infrastructure, funding and accountability. They provided practical help themselves or linked groups to practical resources.

Developing infrastructure

Infrastructure (or the absence of infrastructure) was identified as an important issue by group members and those who supported them. Access to funding, affiliation to national charities, and the groups' ethos and organisational style were all linked to the way in which they were structured. Most practitioners from voluntary sector and social care agencies and national charities helped groups address structural issues in different ways. Health professionals were less likely to get involved in this aspect of groups.

Nearly half of the practitioner sample (n=10) provided templates for constitutions, financial regulations, rules and policies to help groups get established and satisfy potential funders: group members could just 'fill in the gaps'. Some practitioners, for instance from national charities, prescribed a specific model of constitution and rules. One group found this helped them to set standards of conduct at group meetings:

> We have some literature [from the national charity] that we use in the group…there are certain principles …we don't ask people direct questions about where they're from or what their position is, what their job is – and we don't talk about politics or religion. (C5)

Other practitioners from grant-giving agencies, national charities and even community organisations were more flexible regarding the specific model but still required some form of constitution, governing officers and committee. Although they spoke of valuing the autonomy, diversity and informality central to the self-help group ethos, their organisations only supported groups with the required structure:

> I wouldn't work with a group that wasn't constituted, I wouldn't work with a group that didn't have a bank account set up with three signatories. I wouldn't work with a group that didn't have a functioning committee. (B12)

Some larger funders also required relevant policies, for instance regarding vulnerable people. Practitioners advised groups on their options and could offer 'some very basic statements' to help them develop policy (B8). As well as this a few voluntary sector and social care practitioners made "template" constitutions available to the groups:

> I've got about three or four different versions of constitutions. (B12)

One group coordinator felt that a constitution "off the shelf" did not adequately reflect their group's purpose. She valued a more reflective approach, used by two practitioners, helping groups to devise tailored structures which expressed their individual ethos and character. The process of reflection helped to increase group solidarity.

> When time is tight, it would be very easy to use templates … we've resisted that temptation so that when groups start up we don't give them, you know, there's your constitution – we actually work with them very much around developing their own thing that makes sense. (A6)

Formal structures were not always necessary for small amounts of funding. Two national charities provided 'starter grants' to groups without the need for a formal structure. This non-prescriptive attitude was regarded as very helpful in getting groups established with an egalitarian ethos and informal, friendly atmosphere:

> They've been really supportive…they let us get on with it…on the whole, doing things our own way. (C3)

A few groups struggled with the process of implementing a structured approach, feeling it cost them their informality and put unnecessary pressure on group leaders before the group was ready:

> To enable us to get funds we had to form a committee and get a constitution… before it was all quite informal and then, once you've got a constitution it can make people take things a bit more seriously…it's like putting a barrier up in between people. (C2)

> It came a little bit too quickly…we were only established a year, we were still teething…we didn't jump in too quickly, we were led in. (C17)

For fear of losing their ethos, a few groups decided not to adopt a formal structure, thereby precluding them from most funding opportunities:

> If you ask for funding, you're tied to things that you've got to do and we thought, we don't want to do that. (C12)

Choice of infrastructure had implications for financial and practical resources.

Increasing access to resources

Assistance with accessing practical and financial resources was highly valued by the groups. Where funding was successfully acquired, a few groups in Essex needed further assistance to ensure they could comply with monitoring and evaluation requirements. People from all sectors helped in this area, including community, charity, school, health and social care practitioners. Here we begin with practical assistance, then look at the help with funding and finally, accountability.

Helping with practical resources

Practitioners helped groups to address a range of practical issues, including printing leaflets, organising an event and borrowing technical equipment. Community agencies and national charities helped with bureaucratic requirements such as public liability insurance and risk assessments. A few practitioners alerted groups to printed resources:

> We have a … *Community Groups Made Easy* booklet. (B8)

> We've got a specialist library which includes books on everything from community fund-raising ideas right through to the …voluntary sector legal handbook. (B7)

The groups' most pressing need, mentioned many times, was for help to find affordable and appropriate venues for their meetings. Problems with suitability such as location and access, along with size, cost or care-takers could be disruptive as groups had to move on. Practical help was greatly valued:

> The biggest thing has been the changing venues. (C2)

> The issue of practical resources I think that can actually help a group enormously if they say, "Oh we can always use the day room on the ward", you know and they don't have to find the money to rent somewhere. (B3)

Several practitioners from community and health care organisations offered groups affordable or, occasionally, free, meeting places:

> That's part of their starter pack, to have a free room for a certain amount of time. (A6)

> I said to them, well, if you want me to, I can get a room here at the hospital… I book it for them for once a month and I normally do it a year at a time. (B4)

In a small number of cases, groups using premises belonging to voluntary or statutory sector organisations became reliant on this facility, identified with it and subject to its rules or arrangements, potentially compromising their identity and autonomy:

> They had somebody who came in and did all the opening and closing and everything for them, and they decided they wanted to be more independent than that, but they still wanted to meet in the premises... maybe they need to move away from meeting in a building that's related to mental health anyway. (B6)

> We were meeting there three times a week, that's now been reduced to once a week…it's different to what we were promised…we can't argue with that …because …we're not paying for the rooms. (C17)

Two groups using rooms within different kinds of community resource centre found them supportive environments, based alongside other groups and getting 'lots of help with publishing stationary and leaflets and things' (C14). Difficulties with meeting rooms stemmed largely from a lack of financial resources.

Increasing access to funding

Three of the 21 groups in this study managed for many years without external funding, but for most of the others funding was a major concern. Most had to pay for their meeting places, either through subscription or external monies, and some wanted funding for their activities. Many needed help to identify sources of funding, complete applications, and deal with the subsequent bureaucracy around accountability (discussed below). Some groups wanted help in all these areas. Practitioners, particularly (but not only) those in the voluntary sector, responded:

> We can provide supports in terms of things like helping them through, holding their hand with funding applications. (B2)

Funding support raised difficult questions for both practitioners and groups. Some practitioners signposted groups to those with the skills to help, although one social care practitioner in Nottingham felt she was not well informed or confident in this area

> I feel personally … scared is a little bit too strong a word, but I don't know what I'm doing when it comes to applying for funding. (B14)

Even well-experienced practitioners sometimes struggled to provide funding support with the right balance between 'hands-on' support and avoiding dependency. The complex nature of funding applications, with their need for "using the right words" and identifying the right outcomes made it hard to build group members' confidence and capacity for this work:

> The thing I find most wearying is money…I'll get a call when the money has run out saying 'Help, we've got no money left, can you help us make an application?' and then it happens again… we try to give them the skills to do it. (A6)

Some groups enjoyed effective and timely support around funding. Speakers, trainers, workshops and surgeries were sometimes available, and a few practitioners urged groups to become as imaginative and self-reliant as possible in this climate of funding cut-backs:

> We've had speakers come to some of our events to talk about different income streams, to talk about generating funds yourselves…grant applications, donations …we've had a session last week about localgiving.com. (B2)

Views differed about how much money was appropriate for self-help groups. Some groups had reservations about applying for too much funding, feeling that their needs could be served by small amounts or that excessive funding would result in unwanted

changes to the group. Practitioners differed: while two voluntary sector practitioners encouraged groups to aim high in their applications, finding them 'not ambitious enough' (B12), another (B6), felt that a small amount of funding 'made the difference', enabling groups to function well. Groups had to be clear, it was said, about what they wanted to achieve and how funding would help them to achieve those goals:

> "I think its people being clear at the beginning about what it is they want to achieve and how the funding will help them achieve it. (B6)

> Rightly or wrongly we try and get groups to apply for as much funding as they can …but this group were so timid…they didn't want to formalise themselves into a legally constituted group…it kind of switched them off because some of the small groups cannot cope with large sums of money. (A4)

A few practitioners felt that large sums of money could change relationships within the groups as they went through a process of "professionalization" to meet funders' requirements or internal tensions as they struggled to manage the money:

> There was one particular organisation that was funded I think that actually it was not a good example, and in fact I think that the funding, if anything, was unhelpful because people started then having arguments about the funding…probably we gave them too much money. (B6)

One of the consequences of funding groups most unwelcome to groups was the nature of measures imposed for purposes of accountability.

Developing accountability

A number of practitioners, mainly from the voluntary sector, worked with groups and funders to demonstrate accountability for funding. In Essex a small number of groups expressed a great deal of frustration and anxiety about demands for monitoring and evaluation, fearful of what they might involve. The Nottingham groups had not generally been asked for monitoring or evaluation from funding agencies, however even here, as the grants manager stated, they could 'fail miserably' with subsequent accounting and book-keeping processes.

> The administrative side was never ending…it's almost as if the success of winning money with and for them, bred its own dependencies….you get into helping them resourcing and there's just a whole field of dependency around that (A9)

Much of the difficulty arose from inappropriate measures imposed by funders. Monitoring processes tend to adopt a target-focused, quantitative framework, which some practitioners felt failed to capture the beneficial impact for individual members:

> I had to explain… that somebody couldn't get out of bed three months ago and now they're active in a group you know, and it's not quantitative. (B12)

A few practitioners were in a position to work directly with funders to develop measures appropriate for the size and purpose of the funding:

> Monitoring should be proportionate to the funds that are being received by the group and the size of the group, so where we can have that conversation with funders, if we can we'll try and negotiate in conjunction with those groups something that will fit for purpose. (B2)

Difficulties also arose from a lack of understanding about why monitoring or evaluation is necessary, what is meant by 'outcomes', what outcomes groups are achieving and how these might be measured. Practitioners helped to address these issues:

> You can suggest to them and give them structures how they can measure it, like how many people are coming, how many people are getting other work, how many people are going to college, how many people are doing this, and then you educate them why we need to know these things. (A8)

Two practitioners described how some groups adopted a creative approach, outside the usual frameworks, enabling them to express the impact of funding in their own way:

> The evaluation has literally ranged from six lines to a whole little booklet with a 'Thank You' card [where] every member signed it, to photographs to a leaflet being produced that people could see and we took all that to the PCT and they thought it was fantastic, because it was grassroots stuff. (B12)

Whether or not groups had a formal infrastructure and funding, they required members who actively worked together to organise the group.

4.4 Encouraging members and group processes

The span of practitioner support

This section covers the support groups received to enhance the leadership, capacity, participation and confidence of their members, then considers group facilitation and dynamics. Once again practitioners may be described as a trainer or capacity-builder but they were also adopting roles as facilitator, mediator, catalyst and critical friend.

Supporting leadership

Many practitioners acknowledged the central importance of leaders within self-help groups. Their personalities, experience and skills were believed to have a powerful effect on the groups' processes, sustainability and impact:

> He's just a very friendly person …I identified him and I thought, you would be really, really good in a group…he's very good at being organised and being the secretary…you've got to have the right personalities. (B4)

Some practitioners saw supporting the leader as a central part of their work with groups. They did this in a variety of different ways but in particular through encouraging members to take more responsibility for group tasks. One to one support was also felt to be helpful, varying from an occasional chat to more regular opportunities to offload:

> [I] say to them actually…have you got your own supervision mechanisms in place? Is there somebody that you can talk to? (B2)

Some practitioners offered or sign-posted leaders to mentoring and leadership training, and valued training that included a focus on the well-being of the group leader:

> We call it leadership training…so its looking at…looking after yourself, looking at what you can offer, recognising your limits and what you're prepared to offer and give…what you do when you do come across a problem, who you go to. (A7)

Many voluntary and national charity organisations organised self-help group network events and workshops, including a regular 'key-members' day' where leaders learnt from and were supported by their peers. Practitioners also occasionally arranged for a new or prospective leader to shadow a current leader to learn the ropes and build their confidence before taking on the task themselves.

Most practitioners sought to reduce the burden upon the leader by encouraging a wider sharing of responsibilities, but sometimes leaders seemed reluctant to relinquish control to other members. Practitioners suggested that this was often due to their personality: despite the burdens some leaders liked to do 'everything *for* people' (A5) or they enjoyed the recognition they received. Some leaders also feared that other members might lack the commitment or capacity to achieve the same high standards:

> If things went wrong – we've built up a very, very good reputation, I cannot sacrifice that. (C6)

Many practitioners felt that the leader was best supported by having an actively involved membership.

Increasing member involvement

Groups displayed different levels of member involvement (see ESTEEM, 2011) and the degree to which responsibilities were shared across a committee and wider membership varied from a great deal to almost nil, with many being somewhere between these two extremes. Some practitioners were anxious to see more active involvement, especially where leaders seemed over-burdened or groups were in a process of transition from being professionally-managed to becoming self-organising. A few practitioners actively

intervened, adopting a variety of techniques. A gently subtle approach, easiest in a new group, involved getting everyone to take on some simple task and only later give this role a name which might have caused alarm before:

> Somebody informally might collect a bit of money to pay for something, then over the course of two or three months that person has been collecting money… so I say 'Oh, right, we have a treasurer then!'… and they suddenly realise 'Oh well, that's not so bad then. (B8)

Practitioners cajoled and encouraged members as they explained the need to relieve the burden upon the leaders, but a couple described taking a tougher line. One spoke of putting people 'on the spot' suggesting they take up new responsibilities, whilst also creating a 'sense of security' by keeping an eye on how confident and safe members were feeling in their new roles. Another spoke of 'threatening' the group with the consequences, including the demise of the group, if they did not support the leader by taking on group tasks:

> It's almost like, if you don't do it…then the group won't have any money for bags of tea and coffee. (B11)

> You can go in… as somebody neutral and just point out, look, you know, your chairman's being doing this, this and this. (B8)

Leaders and practitioners were aware that lack of active participation was often explained by poor health, limited skills, low confidence and occasionally, cultural factors. Practitioners' encouragement, coaching and training helped, but as mentioned earlier, some groups remained fairly reliant on long term support from volunteers, their minority ethnic community members or professionals at least partly because of their own support needs:

> Two of the parents on the committee are special needs themselves. (C6)

The practitioners' goal was generally to promote members' participation as much as possible and they sought to increase capacity and confidence.

Increasing capacity through training, coaching and peer learning

Practitioners frequently sought to develop the groups' confidence and provide them with the necessary tools so they could be largely self-reliant. Most practitioners from local voluntary sector and national charity organisations as well as some in social care agencies offered a range of training to group members, or where they could not meet the needs they could generally signpost to training elsewhere. Some practitioners made themselves available as needed, adopting a coaching approach where members led the process:

> What I'll do is, we give them tools, we give them the tools to do it for themselves. (B12)

> It is about developing skills…it's about empowering people to do things for themselves rather than us just saying, 'Oh yeah, we'll write that for you'. (B7)

Training covered committee roles but also other skills useful in groups and personal development. Topics included listening, assertiveness, confidentiality, book-keeping, marketing, computer and English language skills. One practitioner preferred to use the term coaching to differentiate this type of formal training from the more informal "coaching" that she also offered to groups. While some training was free, some involved a cost:

> We can signpost to any training really it is just depends on the resources that they've got to pay for that training. So, for example, safeguarding training is offered currently locally for free by our county colleagues, we would cascade that through every self-help group that's signed up into membership. (B7)

As we noted above, building capacity in fund-raising was particularly challenging:

> I have failed consistently with building capacity around applying for funds, now not with everybody, because we run courses on funding applications and how to get funds and some groups have gone away and done it and they've been brilliant, but there are others who literally [we] just can't get them to make that leap. (A6)

Training was sometimes offered only to officers, but at other times all group members and even practitioners as well were included, increasing their sense of solidarity. One practitioner especially enjoyed this opportunity:

> There was a good group of us, people still talk about it now…we all went along as participants and I thought that was great. (B13)

A few voluntary sector and national charity organisations created opportunities for groups to learn from others in similar situations. One practitioner spoke of parents training and mentoring their peers. New or potential leaders learnt from those more experienced (mentioned above). Peer learning across groups through local or regional network events was said to be especially helpful when groups were starting, but continued to be a valued way of getting useful tips and new ideas:

> We do try and have network meetings, you know, where all the groups in an area will come together, and that's good for them, obviously, because they're sharing and meeting new people … but it's also a good way of focusing on a topic and looking at something in depth. (A1)

Being impartial but critical friends

Sometimes practitioners helped to develop capacity by adopting an informal position as a critical friend. They offered constructive but not prescriptive suggestions of alternative ways of working the group might consider:

> I do visit a lot of groups but I don't tend to make a judgement. I might say to them, you know, have you thought about it, would you like to? (A1)

Making group members aware of difficult issues, particularly in relation to the burdens group leaders were experiencing, was a common area the role of a critical friend would tackle:

> You can go in and … as somebody neutral and just point out, look, you know, your chairman's been doing this, this and this, you know, he's doing everything and with not any support. (B8)

Being regarded as independent and impartial to the group were key to the role of a critical friend, as it was this distance that permitted the practitioner to be able to ask and raise challenging issues:

> Just having an outside perspective really…being that independent, but yet confidential ear, if you like. It's easy for me because I'm not directly involved in the personalities to actually sit with a group of two or three and say, had you thought about this, had you thought about that? (B7)

> Through conversation and through being flexible and being open to what the group is saying and listening to that group, and very much prioritising what the group themselves are doing and listening carefully about what they are saying, then we might identify other opportunities for them. (B2)

Offering affirmation and encouragement

A range of practitioners increased the confidence and capacity of groups by their recurring affirmation and encouragement. Some practitioners were in a position to publicly highlight the work of groups within their local communities.

> Verbally reminding them of how great it is what they're doing. (B14)

> Every year we hold a …big celebration in the town hall…with the mayor… Groups nominate people from within their organisations to receive certificates to celebrate the work that they had done, so then it can be an achievement and a joy about what people are doing and the supports that they are providing. (B2)

Addressing threats to continuity: group dynamics and loss of committee members

Practitioners approach and job, in some cases, led to their close involvement in group processes, this could include facilitation, mediation or even temporarily taking on committee roles. Practitioners' differed in their views about when, how and why they should get involved in this way.

A few practitioners acted in a mediating role when troubled group dynamics disrupted meetings or threatened the group's future. Most participating groups in Essex had at some point experienced tensions, for instance relating to managing differing member expectations or group etiquette and needed an "impartial person" to come in and mediate (B7). Often groups were aware of the issues involved and wanted some advice:

> That would be part of my role to help them try and come to an agreement and find peace again and work together, and usually that resolves itself… They would just come to me for support and guidance and help with sorting it out. (A3)

> We've had a couple of groups that got to breaking point because of the control issues with personalities, so we've had to negotiate that and that's where a lot of time and support comes in. (B12)

The Nottingham groups reported far fewer difficulties in this area and only one had required the input of a practitioner in the resolution of such problems.

At times of crisis practitioners from voluntary sector and national charity organisations might intervene in order to keep a group afloat: "rather than fold, we step in" (B11). This could involve taking on a committee role that nobody will fill or doing some practical tasks that the leader cannot cope with at that point:

> An individual feeling isolated or burnt out, that's very much something that we can assist with. We can help with things like identifying the opportunities, completing applications…administrative supports. (B2)

One practitioner expressed caution, feeling that this was only a valid response where the group was still feasible, so where meetings had "fizzled out" the preferred option was to close the group. An alternative way of addressing this type of crisis, perceived to be more in keeping with the ethos of self-help, was described by a national charity that encouraged other, well-functioning local groups to step in when needed, particularly as the group got started:

> With their help they can actually do the running of the [group] … for the first six months or what have you and we can establish a group and we're not pouncing on people to take on these roles. (A3)

Sometimes practitioners were involved in the groups' governing bodies, while others saw this as inappropriate. Most practitioners felt that groups should be directed by the members:

> Ultimately as a self-help group the decisions have to be made by the members. (B2)

> I was very much that I wasn't going to the chairperson or secretary, it was very much their group. (B4)

However, some said that they would 'step in' to a group's committee 'taking on some of those roles' in order to keep a group running. Indeed one practitioner whilst stressing the centrality of member control added that in his view up to half of the management could appropriately comprise practitioners in certain circumstances such as agencies run for and by refugees and asylum seekers who are not in a position to organise themselves:

> Self-help to me is controlled by those that benefit, and a lot of things are named as self-help but you look at trustee boards or the governing bodies of these things and know that they're not…for me, it's a minimum …[of] 50% of the governing ie decision-making function. (A9)

The ESTEEM groups had very few practitioners on committees. One group asked a member to step down when they felt that her new job may result in a conflict of interest:

> So, when I then got that job my involvement with the [name] self-help group was then like a conflict of interests, so I had to be willing to come off the committee of the [name] self-help group and….but I was allowed to still be part of the organisation, but not, you know, any particular role. (B1)

Facilitating meetings

A more common way in which practitioners supported group processes was by facilitating and organising meetings. In this context of self-organising self-help groups these practitioners were sometimes motivated by the belief that groups focused on certain health or social issues needed continued professional support. Others wished to start up groups which could then become self-organising. Some of these practitioners felt that the distinction between self-organising self-help groups and professionally-managed groups was not always useful. Others did not agree with this attitude. First, some practitioners felt that professionally-managed groups find it difficult or even impossible to become self-reliant:

> If you try and do everything for them, it's not going to help them…If they don't do things for themselves [from] day one, then they're not going to last. (B13)
> Going from like a therapist-led group to a self-run group, I think that doesn't work, I think that's very difficult. (B14)

One practitioner was learning this by his own experience:

> I don't think they lack the skills, knowledge or experience. I don't know what it is, I don't know what the stumbling block is, but there's something that just can't get them to move from A to B, and I think to them it's a comfort blanket. (B9)

A few practitioners felt undermined by the expectation increasingly imposed on them to establish and promote member-led groups. Not only was this difficult to achieve, but one had a view based on her experience that people with mental health problems benefited from professional support and facilitation (see below, section five).

This adds to the continuing debate about autonomy and dependency (discussed below, section 5). Some practitioners deliberately adopted a more low-key, link and advisory role where they supported group processes without actually taking part in them. They felt confident that the groups would continue if they should leave their posts:

> I've deliberately tried to stay as far back as I can and to try and encourage them to be self-managing…I think for it to be self-perpetuating, if you can stay as far back as you can but just be there to advise. (B4)

> Being on tap and not on top is very important …you're there for them to use as a resource, not to be part of that dynamic. (A6)

Encouraging inclusive practice

One aspect of advice for group processes that practitioners sometimes got involved in concerned inclusive practices. This was a challenging area (discussed in section five below), where practitioners had to be sensitive to the exclusive purpose of the group (e.g. a Kurdish women's group) and the informality of most groups which did nothing purposively to exclude but may reflect a particular socio-economic and ethnic population. Practitioners meanwhile had a wider awareness of exclusionary processes and a professional obligation to address them, but no easy solutions:

> It's part and parcel - we eat and breathe equality issues, they don't. (B9)

> I think there's more thought that needs to go into that really. (B13)

Groups with a specific minority ethnic population benefited from one practitioner's organisation which always tailored support to the particular needs of the group, regardless of what they were:

> If it were a group with BME interests we would provide them with supports in that area, and it would very much be a response to what that group needed… It's not about changing the way we work with an organisation, but it's about identifying the most appropriate supports for that organisation. (B2)

Tailored support for groups in the form of relevant information was invaluable to nearly all groups.

4.5 Enhancing and sharing expertise

The span of practitioner support

Practitioners increased the knowledge and understanding of group members, practitioners, local professionals and communities in many ways, acting as educators but also often benefiting from an exchange of learning for personal and professional benefit.

Information and learning for group members

An important way in which practitioners of different backgrounds supported groups was in sharing information and increasing their understanding of both their health or social concerns and the local resources available to them.

Information and understanding relating to health was provided by practitioners in various ways. A wide range of practitioners, such as nutritionists, podiatrists, dental hygienists, consultants and GPs gave presentations to small groups or, occasionally, at an Annual General Meeting or other large event, generally on a once-off basis. Sometimes practitioners used their contacts to access and arrange these speakers at the groups' request:

> They'd use us as a resource to say, 'Look, we're planning to do a day on this' or 'We're planning to do an evening on this, who would be the best people to involve, who should we ask?' and then we could say, 'Oh right, well you could go to so and so. (B3)

Those practitioners closely linked to the groups and known to the members gave clinical information and advice in a more informal way to individuals at group meetings or, occasionally, outside meetings to the group leader:

> We then break for tea and coffee and that's when people come up to me and have a chat and say, 'Can I just speak to you for five minutes?' and then we'll have a quiet sort of.. (B4)

> He does quite often, well, sometimes, just give me a ring or send an e-mail about something that's come his way that he doesn't really understand and thinks that I might - and vice versa. (B5)

Health and social care practitioners were also able to use their group visits to correct misinformation about medical advances, often gathered from the internet or newspapers:

> Somebody's read something on the internet or they'll bring in something out of the Daily Mail and it will be this new wonder drug…I do feel that it's my place, to actually say, 'Well, yes, but it's actually only been tried on a couple of rats in a laboratory. (B4)

A range of printed information was provided by local practitioners and the national charity organisations, and some voluntary sector agencies allowed groups to use their premises as a repository of clinical information easily accessible to group members.

> One of our groups here who meet in this meeting room has got a library of specialist books for the condition that they support. (B7)

The contribution of clinical expertise was valued highly by many groups. Many groups saw their purpose as both sharing information and providing peer support, giving equal weight to each. Although a few groups did not ever invite speakers, some invited speakers to almost every meeting:

> I think the health [speakers]…are the most interesting, that's the one you look forward to…Most are health-related. (C16)

The knowledge gained through the groups was not limited to the clinical side of their condition, but addressed wider aspects of the members' lives. Presentations from practitioners with expertise in welfare benefits, transport or even leisure opportunities were welcome:

> I attended their recent meeting to talk about different opportunities…things like a local transport scheme, or shop mobility, things like that. (R2)

> We sometimes get information from other groups or from community centres about some trips – we will come here and tell the group about it and see does anybody want to go. (C19)

On rare occasions groups had been asked to pay for an invited speaker, or at least reimburse their costs, making it harder to find appropriate presenters for evening meetings:

> We did find …people were less willing to come out …and do these presentations at night. And if they do, some of them actually want to be paid for that. (B10)

> Once we had a really expensive speaker, we didn't know they were going to ask for so much until we got the bill in afterwards, and that was a shock…that set us back a long while afterwards. (B1)

The exchange of learning

The health practitioners in the study emphasised the reciprocal nature of the learning. By attending and supporting self-help groups they also learnt more about the people who experienced the difficulties and the strategies they employed to deal with them. There was an exchange, rather than a one-way process of education and learning, which could inform service and personal development (see Roles and Rewards and benefits section x).

> There are always things that you can learn from groups like that…I would say [it] is a two way process of giving and receiving information from both parties. (B3)

The relationships between groups and practitioners, combined with the groups' organisational capacity and confidence, were the bedrock on which groups could launch their profile locally and influence those they wished to reach.

4.6 Increasing connections, credibility and influence

The span of practitioner support

Practitioners connected groups with service providers, other self-help groups and community resources, helping to increase their capacity and membership. Practitioners helped groups to have voice and influence, reaching service providers and their local communities. Some practitioners were signposting and informing while others were facilitating new relationships, sometimes advocating on the groups' behalf.

Connecting groups with health, social care and other service providers

Several group leaders expressed frustration about how difficult it was to identify and make contact with those in health, social care and the local authority to whom they wished to make complaints and suggestions or who could help, for instance as advisors, speakers and potential partners:

> They've all got people below them and they say you need such and such and you can't get through to who you need – you just keep hitting a brick wall. (C2)

> It's very difficult to get a relationship with the Trust, I mean they're just not available. (C11)

Many practitioners within these services and community agencies felt that they had an important linking or signposting role, enabling groups to access and build useful relationships with the appropriate people. Sometimes, practitioners acted on the groups' behalf, making their requests for them; sometimes they simply made the link, enabling groups to negotiate what they wanted:

> If they wanted a speaker, because I've got the contacts in the hospital I would do that sort of thing. (B4)

> It may be that we need to signpost them to somebody else who has certain expertise that can support them, and that is then dependent upon the relationship that they build with [them]. (B2)

Some practitioners and group leaders felt that it was easier for groups to be taken seriously if they had a 'stamp' of legitimacy which could derive from being connected to a bigger agency, a national charity or to the PCT itself. The nature of these connections could cause tension if they threatened group autonomy, but two groups were delighted with recognition of their group on NHS posters:

> We had trouble getting the poster up, people said – oh, are you people from the PCT? They let [us] use their logo and they're strict, you know, it's got to be in the top right hand corner.. ...but at least we can say, you know, we're not paid by the PCT but.... That helps a bit (C15).

> That is a selection of the top neurological illnesses in the area, their representatives. And that's quite good, they've just completed a poster and we're on the bottom of that, but we're on there…We're on there to go to all doctors' surgeries and everything like that, so we're there. (B1)

Sometimes practitioners could not help to create these valuable links because of gaps in their knowledge or the opaque nature of statutory structures. Communication problems with health services were most commonly mentioned:

> The best communication we have is with education…Social care, a little bit, health, not very much at all. (B11)

Promoting and publicising groups within health, social care and other services

Some practitioners from all sectors went further and sought to promote and publicise the groups, sometimes advocating on their behalf. This was important because a number of groups had little success when they tried to publicise their group meetings and activities, for instance at the GP surgery, and some blamed this for their lack of success in attracting new members. One group whose numbers had seriously declined felt that its problems could be addressed through reviewing their advertising materials:

> If we solved the members we'd solve the finance…if I had a plan at all it would be to …send the redone posters out. (C5)

This could result in anger and frustration with clinics and health centres that could or would not display material. Practitioners from across the sectors helped to develop and distribute a variety of newsletters, posters and leaflets:

> We do try and do a health newsletter every couple of months which goes out to all the self-help groups, but goes out wider as well…that goes to GPs and pharmacists…we make people aware of…. 'Here's some groups…here's the information'. (B8)

> You have to start plugging things and sending posters out to people…up and around the centre and posting them…to community mental health teams. (B14)

Even practitioners were not always successful in getting publicity distributed. GPs for instance received so many leaflets 'it's not as easy as that' to get group leaflets displayed (A1). Health and social care colleagues did not always have a benign view of self-help groups (see 'tensions' below) and supportive practitioners sought to increase understanding of the groups' value:

> As a professional involved with the self-help group, I think we can stick up for the group a bit. (B1)

> I do get a bit annoyed when people don't recognise the value of peer support and professionals think they have all the answers, because I think there's a place for everybody. There's obviously a place for professionals but I think its important that they do also listen to what people who've been through the same journey have got to offer too. (A7)

This advocacy role was particularly needed when groups found GPs and other health and social care professionals were reluctant to inform potential members about the groups which might have helped them.

Increasing access to self-help groups

Several group members felt that some health and social care professionals often failed to inform service users about self-help groups, either for lack of information or because they actively resisted doing so:

> I don't know what it is, there is this resistance in signposting…new patients. (C12)

Practitioners participating in this study, including those within health and social care services, agreed that there was sometimes a resistance, partly explained by the way self-help groups might inadvertently place clinicians outside their comfort-zone or might be perceived to hinder recovery (discussed below). Other group members said that clinicians they knew personally ('my own psychiatric consultant', 'my GP') were very supportive of the group and did pass on information, as did several others:

> The GU clinic…the guy that does the male side of it has got our service leaflet in his drawer and he will give it to people. (C21)

> My GP is fantastic – she'll tell people. (C12)

There was some ambiguity about what it was health and social care professionals were doing. Some group members, practitioners and service providers talked of 'signposting' or simply giving information about the group, allowing the service user to decide whether or not to attend. Others spoke of 'referring' service users which suggests a closer relationship between the clinician or professional and the group, possibly perceiving the group as another service to which they were sending their service user:

> We set it up and work very closely with the health visitors, the doctor referrals because we're linked with mental health within the community mental health team… sometimes the psychiatrists actually do the direct referral. (C20)

> We've had GPs' referrals, we've had community mental health team referrals or psychiatric nurses. (C14)

While a few groups did not question this relationship, one group for children with special educational needs found that 'referrals' from education services proved to be overwhelming:

> It's getting to the stage where I feel like I'm drowning…We do it for nothing… people start looking at you as if you're another service. (C6)

Overall, there appeared to be too little signposting and for at least one group, too many referrals, a dichotomy discussed below (Tensions). Sometimes groups wanted signposting for themselves to find out about local resources and how to increase their local profile.

Promoting community and self-help group networks

Groups that wished to develop or were floundering in some way benefited greatly when a practitioner linked them to relevant networks, organisations, individuals and other self-help groups. By creating these links, community-based practitioners enabled groups to increase and strengthen their profile within the local community:

> With the help of [practitioner's agency] … we're linked to the national group but we're also linked to a lot of local groups, so we are much stronger in that way... we developed community status and now we're involved in lots of things. (C7)

Practitioners with wide-ranging networks helped groups to access local resources, for instance around funding and training opportunities. Tailoring this information and signposting to the specific needs of each group was regarded as important:

> Identifying areas of interest is key …It's about making sure again that you are responding to the individual needs of that group and then linking them up with services that may support them. (B2)

Not all practitioners, even from voluntary sector agencies, were well-informed about local resources or effective communicators, limiting the potential for networking:

> They didn't even mention when they came to visit that they did actually have a training programme. (B14)

Several groups participating in the study described numerous ways in which they linked with or wished to work alongside other local self-help groups. This helped them to learn from each other, arrange events and speakers more effectively, and sometimes to have a greater impact in the community. These opportunities were especially prevalent in Nottingham due to the role of SHN at which regular network meetings and events were held. Most national charity practitioners sought to promote these inter-group relationships, for instance through newsletters, events, meetings or online:

> We have … networking events for groups coming together…I think people like meeting other people in other groups and that's something that's on offer here…we have a new group evening and they get to meet other new groups so and it's usually most new groups will come to that…it's quite a lot of fun and they get food and you know it's very informal and there's some fun exercises to do to get people talking. (A6)

> We have a bi-monthly newsletter which is called 'Group Talk' and that is groups sharing with other groups, so they're encouraged to have that wider network and a lot of them do that informally on e-mail. (A1)

A few practitioners also identified groups that they felt could assist or act as a role model for other groups. One practitioner observed that groups usually responded very positively to this opportunity to help others:

> They just sort of swap information and one group would give a rundown of how they started and where they are and the highs and lows of things. (B12)

> We did go to the one that they run in [place name] because theirs is a very, very big group and we said to them, 'Could we come along and see how you run your group?' you know, just to get some ideas and maybe just to make some links." (B4)

As well as wanting to be connected with other groups and local resources, many groups wanted practitioners to help them identify channels for expressing their views about local services.

Linking groups with opportunities to be heard

Many groups, and in particular, but not solely, group leaders, wanted to make a contribution to improving public sector services. Some practitioners from all sectors linked them to the opportunities they wanted, informing them about service consultations and public and patient involvement processes. For some practitioners this was a small part of their role while others were employed to promote community and service user engagement:

> To make them aware of opportunities that they could really provide important feedback …[name of group] have become involved with the patient and public engagement forums with our GP consortia as a result of finding out about it through our networks. (B2)

> We're setting up new citizen reference panels which feed into the clinical commissioning group boards. (B8)

Several practitioners did not merely inform groups but actively encouraged and supported what they saw as an important contribution to service and policy development. A clinical

lead practitioner (B5) remarked how 'really useful' one self-help group was to research and commissioning in her topic area. A few practitioners and group leaders emphasised how much influence the groups were having:

> They come to us knowing that our parents are reasonably articulate and well aware of what's happening with disabled children in the county. (B11)

> We've established quite a valuable name for ourselves so quite often we get people wanting to come … to get their views on whatever the issue of the time is – consultation events. (B10)

Others were more likely to speak on behalf of groups, taking their views to committees or even to lobby government officials:

> One of our roles … is to act as a representative at various committees. (B2)

> I represent them and tell the government this is what is happening. (A8)

5. Complexities and tensions

5.1 The challenges of practitioner support

This section presents the questions and challenges facing practitioners in three broad areas: their working relationships with self-help groups, the changing support needs of groups through their evolutionary journey, and facilitation to achieve inclusive and participatory practice for group members with different health conditions, cultural backgrounds and social circumstances. Then we identify challenges around group involvement. Finally, the section presents a spectrum of autonomy, drawing out the complexity around the self-organising and member-led nature of self-help groups.

5.2 Working relationships between self-help groups and practitioners

Challenges in working relationships

The complexities and tensions in working relationships between self-help groups and practitioners discussed here include divergent operational practices, practitioner resistance to getting involved, boundary issues and tensions between national charities and their affiliated groups.

Divergent practice

Data from practitioners highlight the need for awareness about the different ways in which self-help groups and professionals tend to work. Groups may operate in ways that challenge practitioners' expectations of professionalism, appearing 'unregulated' and disordered. Practitioners' disquiet may be explained or exacerbated by a failure to distinguish between self-help groups and services:

> The healthcare professionals expect to get a service provider on the end of the phone and in fact a toddler answers and says he'll go and get mummy. (B12)

Issues arose around the timing of activities. Group members' health conditions might mean that they 'struggle….. in the morning' making attendance at meetings or events, at times that would seem reasonable to practitioners, difficult for many self-help groups. For conditions like ME, long meetings without breaks were not feasible:

> Going along to a committee meeting or coming along here, I mean for those of us who are sufferers, that's probably our energy for the whole day. (C16)

Timescale was seen as a particular issue for groups involved in consultations. Many of the study groups met monthly and some less frequently, so they may be unable to provide feedback to consultation exercises for several weeks:

> If you need to consult properly with the community sector then you need two or three months… some groups only meet once a month, so to consult, you know,

> you've got to get the information out, and you may have just missed a meeting, so you've got a month to wait and it may be … the end of the following month before they get any replies back. So if they don't allow that time then they're not going to get meaningful results. (B8)

Tensions around timing could arise in other ways. Practitioners might find delays in getting a response to requests, for example, to attend a meeting. Although groups' timescales could be exacerbated by practical matters such as their health conditions, they frequently reflected a deeply-held ethos of involving all members in group decisions:

> We'd talk about [decisions] at the meeting…everyone has their say…we decide between us diplomatically. (C3)

Indeed this was the case in the current research where more than one group went through processes of discussion over several months before reaching a consensus as to whether or not to participate. Delays were not indicative of apathy or the group's lack of desire to develop a relationship.

On the other hand, practitioners could be under pressure to work fast and sometimes felt that they lacked the time to attend meetings and provide the level of support that they would like:

> I sometimes wish there was another couple of me's around, because there's a few of the men in the group and they really would like to talk to a health professional and there is only me. (B4)

> I visit them at least once a year in person if not more because I have 15 branches across that area and I have other responsibilities as well as the branches, not just them that I work with so there's a limit what we can do. (A3)

Differences in working practices partly explained the resistance of some practitioners to supporting self-help groups.

Practitioner's 'resistance' to engaging with self-help groups

Some participants believed that health practitioners could be hesitant to work with self-help groups. Explanations included a fear of losing their status as an expert:

> They're a little bit scared of going into a group like that. (B5)

> The biggest problem they have with it is that it … undermines their expertise, or that people just get together and bitch about them. (B12)

Their professional expertise was sometimes challenged:

> The one that comes up most commonly, gets thrown at us, is…'Have you got diabetes? Do you know what you're talking about?' And it's, no, I don't have diabetes but I do know what I'm talking about, because a lot of what we're imparting as knowledge is our actual knowledge that we've been taught and that we are constantly striving to keep updated, but actually a lot of what we're talking about is anecdotal information from people like you guys out there…There's one or two that just sort of go, 'Well, you see, you've not got it, you don't understand'. (B3)

Some group leaders would step in to mediate these challenges: 'I had to stop it' (C16). Practitioners feared losing their institutional protection in other ways, for example compromising their professional indemnity or with regards to the perceived risks attached to group activities:

> They're scared of their own indemnity. Someone's going to ask them something difficult, they might say the wrong thing … they might be contradicting some other clinician's input. (B5).

> There are risks, if there's something that you think would be a real cause for concern, you wouldn't be able to get involved with that, we do have statutory obligations, and also to point out, you know, if people are doing any kind of risky sort of business. (B13)

A few participants suggested that practitioners questioned whether self-help groups were improving their members' health. One health practitioner supporting a self-help group faced resistance from a colleague who thought the group was failing to aid group members' recovery, which was a concern she too had struggled with:

> I know my physio colleague in the team, he's not keen on self-help groups, because he wonders if it holds them back… I can see his side…there is a little bit of animosity between the working environment and the self-help group…our aim is to help people to get better or to get back into what they were doing. I think the [name of group] aim is to support people because they've got the illness. (B1)

> It contravenes their method of treatment…[members] give wrong advice about medicine and things like that. (B12)

Boundary issues were frequently raised as an area of potential tension and complexity.

Boundary issues

Many practitioners felt that their work with self-help groups could raise challenges in relation to boundaries. One (A6) spoke of seeing practitioners confused about 'which hat they've put on that day'.

> I've seen a number of times where a professional in the group that's not a self-help worker, is maybe a really helpful nurse or a health professional…hear something in the group … they think what am I meant to do? (A6)

Several practitioners spoke about challenges in relation to confidentiality and professional conduct:

> The group has confidentiality clauses so are you signed up to that or are you not? …I've seen a very sad case of nurse hearing something in a group where it left her quite devastated about what to do about it and it wasn't a protection issue, it was a decision about whether somebody was going to go for treatment or not… she had a real dilemma on her hands whether she should go back and say to her consultant he's not going to come back. (A6)

Health practitioners were often faced with misunderstandings about medical information at group meetings, as mentioned earlier. Whilst some clearly believed that their role was to dispel these errors, others felt that this could be a delicate matter that was better dealt with on a one-to-one basis:

> You hear people stand up and talk about things like and you think, you've not really got the full picture there, but it wasn't my place to sort of go, "Oh hang on a minute, actually"…if it was something that I felt was going to affect their [condition] and the way they were managed I would try to catch them at the end and sort of go… I don't want to say it in front of everybody, but actually what you said there was factually incorrect. (B3)

Practitioners also raised issues around what it is appropriate and permissible to share with group members in relation to organisational and service issues:

> I told the patients this and I thought afterwards, is this something actually I probably should have shared?...Was it my place to kind of share that? So it was quite a political thing really. (B4)

> There's these sort of governance issues that hit you because you're working in it and I sometimes think I don't really want to be sent a list of everyone's names and addresses, because it's automatic for them to do it and it's OK for that group, but it goes against my grain to have all that information, and I don't really want it, and I don't like to say, please don't send it to me, because then that sounds like you don't want to play that game…this is their group but it's being held on NHS premises…It is difficult, but you have to get a bit pragmatic about it otherwise these things won't happen. I mean it's not dangerous in that remit and I do always point out, this is my difficulty, and I can't involve myself with that conversation. (B5)

Boundary issues had occurred for voluntary sector practitioners when group members had misinterpreted their relationships with them as friendships:

> There's been occasions where somebody's said you know if you can't drop it off we'll come and pick it up from your home and I have to say no you can't do that. I'm really sorry, but I can't give you my address … Once when I first started working here after about 18 months, I took some time off sick and then he was told I was off sick and he came to my house. (B10)

> People can mistakenly think you're their friend. (A6)

Practitioners felt that the most effective way of managing and maintaining boundaries and avoiding this type of confusion was to be clear from the outset about what they could offer to groups and the limits to their relationship:

> Self-help workers have to be very, very clear about the boundaries and I think if they're unclear you could get into all sorts of trouble… You need to give thought to that and be very, very clear with people. (A6)

> It's being clear what's expected of that individual, are they there… because they are seen to be contributing something from a professional viewpoint…. People need to be clear from the outset what's expected of them …otherwise it's difficult to know whether to intervene or not. (B6)

National charity organisations provided support from a distance but again, lack of clarity or agreement about respective roles could cause tensions.

Relationships between national charities and their local groups

There were some tensions specific to those groups that were affiliated to national charities, although it should be noted that these did not apply to all the nationals, some of whom had excellent and supportive relationships with their local groups. Two of these groups believed that their informal peer support role was not understood and that their national body lacked any respect for or appreciation of what they and other local groups were doing:

> We've just had the most awful letter from them….the tone of it was horrendous …. I said, I think you've forgotten we're volunteers, we're not getting paid to do this job and we can't be treated like minions in an office. (C2)

> We're not trusted anymore….we give up our time …and then we get it thrown back in our face…nobody here is a paid member, we're all volunteers (C7)

Members of one group felt that the aim of the national organisation was to homogenise affiliated branches, lacking understanding of their local character and knowledge of how to best respond to their community's need:

> At the end of the day we are here to look after the people of [place]…and through that we are able to achieve things for the people of [place]…we're not really supposed to say we're from the [place] branch of [group name]… and that means that a lot of what we've achieved locally really will be lost…I mean it's far easier for the national if we all work to the same model if we start to have different like you say a different character it is far more difficult for them to handle us I suppose but if they want to achieve things in our local community for [the condition] then they need to be able to allow us to have some leeway. (C7)

One group leader (C7) conceded that this may be due to a concern about 'quality assurance' and maintaining standards. One voluntary sector practitioner who had worked extensively with affiliated groups felt that improved understanding would go a long way to resolving many of the tensions between nationals and their branches:

> If you've got parent organisations and then you've got groups and they start acting like adolescents and parents and if the national isn't sensitive enough they start having fights on their hands around rules, around things you argue with parents… It's setting up that relationship and I think if they work at a distance and then they come in they've got no understanding of where that was coming from…it explodes…If you expect people to adhere to [rules] you need to have some sort of relationship with them. (A6).

There were specific funding issues for some of the groups affiliated to national charities. Although not all of the ESTEEM groups had had such problems, some felt that local groups were seen simply as a source of funding for the parent organisation, having to donate back to the national the majority of locally raised money:

> The national organisation get a lot of funds from things like the lottery but a lot of our local funds go to the national…we always feel compelled to give to the national but…it's becoming more and more now that it's almost as if were not allowed to say or do as we please it's almost as if they see us an arm of their organisation and almost as if we're only there to raise funds for them. (C7)

Affiliation could also lead to restrictions upon the sources of funding for which local branches could apply.

> Some of our funds do allow groups such as that to apply for funding but in our constitution they've got to be locally constituted to the County…if it's a national organisation that's just got a branch we can't fund sadly you know there's local branches that do do a lot of good work but the way they are set up the branches raise money for national, giving money to a top tier we can't help them. (A4)

> If [branches] identify something they come and tell me about it and then we'd work with the fundraising team to put an application in because it's all under the same charity number, we have to work together in case we inadvertently duplicate any applications. (A3)

One practitioner working for a national charity (A1) felt that it was part of their role to discuss and where possible, help groups with disaffiliation or closure with groups considering these steps.

The next section considers the different kinds of support groups needed at these different times.

5.3 The evolutionary journey

Challenges for practitioners

Complexities and tensions described here cover the changes from the time when groups were first established, with or without significant practitioner involvement, to the time of transition as they gain independence, to winding up and closing the group.

Helping groups to get established

Several practitioners took on the role of 'catalyst' helping to start up groups. Most practitioners felt that groups needed particularly high levels of support at this stage, while a few from health and social care spoke of being quite directive:

> They require a degree of support that an established group wouldn't. (B2)

> You do take quite a firm lead in the early days. (B13)

Many groups agreed with this and made extensive use of 'starter packs' and 'starter grants'. Most groups received some external support and guidance but not all:

> It all just grew up…that goes back to them identifying the need for themselves. (C10)

Sometimes self-help groups were 'triggered' by self-management courses, other training and in one case by a consultation on health-related publicity. Service users involved wanted to continue meeting up and were often encouraged by health or other practitioners keen to see long term support. Whatever the spark, practitioners offered guidance, for instance around what to expect and whether or not to affiliate to a national charity:

> It was a new group starting and they were deciding whether they were going independent or whether they became part of the Stroke Association Group… so we both went through it together with them and said, 'Look, these are the options.' (B8)

> I was approached by members here who were very keen to sort of get that off the ground but needed to know how to. (B13)

To avoid the boundary tensions described above, participants said that practitioners had to be clear and open with the membership right from the outset about how they intended to be involved:

> Knowing what your remit is from the start, with setting up a self-help group is key. (B14)

Transition to independence and sustainability

A few practitioners had played a role in helping groups as support from health and social care professionals was withdrawn, sometimes unexpectedly. To support the process of transition, practitioners helped members to get accustomed to and equipped for their future roles and responsibilities, getting them to reflect on the choices and possibilities ahead of them:

> There's no project worker, what is it going to look like? What is most important for you?...how much is it going to cost a week, a month? (A11)

Practitioners had sometimes struggled with supporting groups through this transition from being a facilitated to a member-led group. We noted earlier participants' view that this journey of transition was often difficult and sometimes led to the group fragmenting:

> The only thing that can be done is to try and keep a link. It's really, really hard because the thing is, you try to make a group run itself, it's like you don't want to be the link because the group's trying to run itself. (B14)

> I think that's the way it's got to go really to become independent and be registered in their own right and then they will have in a way to take on some of the responsibilities of running the group and making sure that it doesn't disappear if I leave…those skills need to be kind of nurtured really. (B10)

Where there was a negative attitude and too little help, preparation and input from those who set up the group the transition was especially hard, and one participating group continued to feel they had been treated badly. Sometimes groups struggled to establish a new identity and direction:

> The group themselves don't feel ready to branch out and meet elsewhere and become their own group. (C17)

> They just turned round and said it was finishing and we'd got to go on our own which was…It was like being dumped. (C9)

Sometimes when the loss of support was unexpected, members turned their anger on those practitioners who had subsequently stepped in to help:

> We gave them such a hard time we needed to let off our steam after being treated so badly but it wasn't their fault we still felt really bad about how we treated [names] when they first came in that day. (C9)

Practitioners spoke about other groups who may not have been professionally facilitated but for various reasons entered a phase where they struggled to keep going. The continued availability of support enabled groups to deal with new challenges:

> Support needs to be on-going throughout the lifetime of the group…[for] any new challenges that might be coming along…So we've seen them go from being quite closed, not by their own making, but because they didn't know what paths to take, to now having a lot of information and a lot of support, and they know that if they need help in any area they can just come and ask us that question, and for them I know that that's incredibly valuable. (B2)

Winding up a group

The fluid, evolving nature of self-help groups meant that the closing and ending of a group is a typical feature of their life-cycle. Some practitioners helped to facilitate this final transition, taking a positive perspective:

> We recognise that groups sometimes have a life and I don't see that as a failure, I see that actually somehow as a greater empowerment if they've actually decided they no longer need that group. (A1)

> You can put a lot of work in and then, you know, they can close down a year later. It may be that it's served a purpose, you know, because … they've set up, they've helped each other …they have moved on and used it for the better. (B8)

On the other hand, there was sometimes little clarity about how practitioners helped group members to consider and bring about closure, and some practitioners seemed keen to keep groups going. A group attended by only one or two regular people did not describe getting any advice about the possibility of closure, and indeed were still being assisted to produce new leaflets in the hope of attracting members.

> Our aim is to keep that group going and however we can do that. (B7)

When national charities and other practitioners found a group unable to appoint officers, they occasionally helped to bring about the groups' closure but at other times stepped in to keep the group going, as described above.

5.4 Facilitating for participatory and inclusive practices

Challenges for practitioners

This section covers the questions asked about when professionals should or should not be involved in facilitating groups. It then considers questions about how and when should inclusive and participatory practice be promoted.

Professional facilitation for groups needing intensive support

Some practitioners' approach and job role encouraged them to take a facilitative position within groups. A few practitioners had experience of professionally-managed groups where they retained control, but they found that employers increasingly expected that professional facilitation should only be a temporary measure to help groups get established:

> The gold star has been getting a group up and running in the community without a professional facilitator…whereas groups that I've done in the past, in other organisations, it's just been taken for granted that I will be running it and I've not been thinking of, eventually they'll be running it themselves, it just hasn't figured. (B14)

A small number of practitioners perceived that other agencies thought their leadership of self-help groups contravened the 'pure self-help', 'user-led' model. They felt undermined by the lack of value attached to professionally-led groups:

> I mean that's what I'd like to see, social services agencies still being able to, you know, to run self-help groups, and that there isn't seen to be such a big contradiction, because I think people feel there is. (B13)

> I get quite concerned with the undermining that's being that's sort of put in the face of professionals and professional input…within a self-help group (B14)

As mentioned earlier, some practitioners felt that professional facilitation was critical to the success of groups for people with mental health and addiction problems. For one, an earlier mental health group fragmented when her facilitation ceased, and she feared for members' health. Similarly, another (C17) was concerned the group leader of an alcohol and drug group was 'in a very vulnerable place' and neither he nor any of the group members were felt to be 'stable enough to be running a group like this':

> Mental health groups is a huge problem because a couple of times we've tried running an anxiety, stress, depression group and it's folded because people aren't prepared to step in and manage it themselves…I think that's one of the very few groups that need a facilitator. (B12)

> For this [drug and alcohol] group …it does need somebody who's a few steps away from what's going on…I don't think that's always the case because I think sometimes …the individuals are more healthy, but maybe just struggling with group issues, can benefit a lot from having to muddle through the group issues

> and learn, but if they've got health issues and particularly mental health issues, it gets a whole lot more complicated. (C17)

Across the four groups of people with serious mental health problems participating in this study, three were self-organising and only one was professionally facilitated. The view of B12 above suggests, however, that the transition from professionally-managed to self-organising status may be especially difficult for people with mental health problems. Our data supports this view as another mental health group compelled to become independent greatly regretted the loss of its professional support.

> We need to have some support worker who will come to group….we need more [support worker involvement] not less (C1)

Another practitioner gave a different perspective, suggesting that professionals who felt facilitators were indispensable devalued peer support:

> I think you are really saying, well, the quality when you talk to each other isn't good enough. (A6).

As mentioned earlier, most practitioners emphasised the importance of promoting group autonomy. Several spoke of staying outside group dynamics and providing clarity about the limits of their role to avoid dependency from the start:

> I don't foster dependency, I make it quite clear that I will work with them and give them all the support they need, but at the end of the day they need to do that themselves. (B12)

Inclusive and participatory practices

We noted earlier differences in the groups' awareness regarding inclusive practices. Practitioners expressed different views about this, acknowledging the need to encourage participation of people from different backgrounds but also feeling that this is difficult and sometimes inappropriate.

One practitioner felt that groups should be challenged if they use diversity discourses to their own advantage or to avoid wider participation:

> I think that with all groups and societies they will use different isms and schisms to their advantage….We have to consider more and more about integrated working…you know people will use different belief systems, culture, you know, gender, for their advantages, and I think we kind of have to play that out. (B9)

Two practitioners highlighted the difficulties of meaningfully engaging with different ethnic groups:

> They're kind of going into, "OK, you're not bringing any Chinese, you're not bringing the Turkish", but they're not kind of supporting us to have more funding so that we will be able to pay for translations, so it's very limited, so all we can only do is talk to them, invite them for a meeting if they can come, and see how best we can be able to, you know, to show what they're facing. (A5)

> There are hard to reach groups…unless you've got a really big population where you can make a point of going to community centres or whatever, it's hard, they're sometimes hard to engage. It doesn't mean to say we should stop trying. (B3)

Another practitioner noted that some self-help groups focused on a specific population so were inherently exclusive:

> I also see it as being quite exclusive, and what I mean by that is the Kurdish Women's Group I worked with in London were made up of and supporting Kurdish women who had suffered domestic violence or forms of violence, so then when grant programmes come in and encourage them to work with wider communities, there's a real contradiction there, they were set up for Kurdish women, they weren't set up for Nigerian women. (A9)

A number of practitioners, however, believed that, where appropriate, they should actively encourage groups to engage more widely and reach out to new populations:

> The idea of training for them is a brilliant idea…being able to make sure that the people who are leading those groups…are able to make sure that they're completely inclusive…that they are reaching the harder to reach. (B3)

> You never want it to become a kind of clique, and you always want it to be sort of open to people from the outside. (B13)

Promoting participatory practice within the group could also be challenging. As the Stage One findings indicated, group leaders' aims and ideas about the purpose of the group sometimes differed from those of the membership, potentially creating internal tensions. Practitioners gave examples of how leaders did not always consult with the members with regards to decision making:

> You could send paperwork out to somebody or email the contact, the chairman or whatever, and if they look at it and they're not interested there's a lot of chance that it won't even filter down to the group…You know, if the main contacts don't bother, you know, if the chairman says, oh, we're not bothered about that, he'll often make a decision for the rest of the group. (B8)

Group leaders were sometimes unwilling to delegate significant tasks or responsibilities to the members, as discussed above, and meanwhile, some members were happy to 'follow': 'some founding leaders don't want to let go' (B7). Group leaders were not

always good at facilitating member involvement in discussions, and some practitioners felt that they could make a useful contribution here:

> There are always the ones who are prepared to speak out and there's the ones who sit quite quiet and meek at the back and you think, you could have a number of things to discuss but you're not getting the chance because you're overwhelmed by these other very strong characters or personalities. (B3)

> You'll get certain people who will be... who prefer it if other people are talking, so they don't get a chance to talk, and when you've got a facilitator they'll be mindful of that, so maybe drop in the odd question to try and help other people have their say. (B14)

A number of group members however felt that one of the unique qualities of self-help groups was that they were attended by different people for different reasons, some of whom, at certain times, may not wish to be involved in the group conversation. The members of one group described how they were highly attuned to when this was the case:

> If somebody's upset and comes into the group all of us can sense it and either we're getting them to talk about it or we leave them to sit in a corner and if they want to talk about it they'll talk about it … we've noticed the fact that they're upset. (C9)

> People are quiet, we're not forcing them to talk, but when they're ready they will talk. (C11)

One practitioner stated how she deliberately refrained from imposing her usual methods in order to let the group work in its own unique way:

> I wouldn't do what they do, but they obviously really like it because otherwise it wouldn't happen…I'm quite amazed every time they do it actually, it obviously works the way they run it. (B4)

5.5 Identifying barriers to effective group involvement in consultation processes

A few practitioners highlighted the difficulties self-help groups had in undertaking consultation and Public and Patient Involvement (PPI) processes meaningfully. Statutory authorities were said to make insufficient arrangements to ensure groups could participate effectively, giving rise to suspicions of tokenism. On the other hand, some groups may lack the capacity or interest to express their views in a way in which they will have impact. Practitioners who attended meetings on behalf of groups may sometimes be helpful.

Several practitioners spoke of tokenism as the same people were involved again and again. While effective involvement helped to boost the morale and energy of a group, a failure to respond to their contribution can create cynicism:

> I've seen groups really flourish if they're involved in things at all levels and conversely… if it's tokenism and they're maybe involved but not listened to, they're not valued, then that can have a really detrimental effect. (A7)

> There's a very strong sense of cynicism among self-help groups that health services and service providers come to them when they need a specific group represented…a tick box exercise (B12)

One practitioner spoke of a group who felt overwhelmed by the number of people approaching them for consultations.

> They were the only ethnic group in the area, so every time somebody wants something they come…and say…'Can you do this consultation?'…they just got consulted out and they said 'Well, we're going to stop doing consultations.' (B8)

Several practitioners saw themselves as having an important function in speaking on behalf of self-help group members, especially in more formal, perhaps strategic meetings. A few spoke of the importance of knowing what group members thought, to make this a valid approach. The same issue arose in Stage one of ESTEEM, where group leaders often attended consultations and external meetings. The need for representation arose partly because group members were said to lack 'understanding' and competence to take part effectively, and partly because those organising the consultations failed to accommodate community participants:

> They feel overpowered by some of these figures and, you know, you have to be able to talk to people like that, in a certain way, and so we can be their voice (B11)

> Unless you put it in front of the right people in the right format, they're not going to go very far (B5)

Two spoke of failures to address communication barriers:

> A lot of the consultation exercise is online, encouraging older people to get into the computers… Have they actually looked at, what about those people who do not speak English that is completely excluded? (A11)

> If they're going to involve peer support groups they need to recognise that perhaps they need to adapt things slightly and maybe talk in a way or communicate in a way or go out of their way to involve people, and there seems to be a sort of resentment of doing that. (A7)

One group overcame the barriers, but appeared to be unusual in this respect:

> They turn up now at our large…conferences with their own stand, all their bumph written out, all their plans of what they're going to do, they know how to talk to a

research community, which is not easy, they understand what we're saying but in a lovely way. They're a really good link between that PPI and the academic. (B5)

6. Benefits

6.1 Benefits of self-help groups

This section will illustrate the wide range of benefits that arise from self-help groups. Groups were perceived to bring advantages to their individual members; the community; practitioners and local services. These included:

- Improved health, well-being, confidence and social activity amongst members
- Promotion of participation and social capital in local areas
- Better uptake and more efficient use of health and social care services
- Provision of opportunities for dissemination of health communications and information
- Increased lay input into consultation processes
- Improved practitioner knowledge

6.1.1 Benefits to Members

The advantages that members had gained from participating in self–help groups were discussed at length in the Stage 1 report and so will only be briefly summarised here. Membership was seen to provide direct health benefits through improving knowledge about health conditions. Attending groups also led to increased confidence, both in terms of social participation and in relationships with clinicians, which in turn were felt to improve clinical outcomes and coping mechanisms:

> A lot of people would say 'I've learned more about epilepsy in three hours than I have in 30 years'. (C7)

Groups also contributed to their members' broader sense of well-being. This might be through addressing the "isolation" that frequently accompanied their diagnosis:

> It was marvellous to come into a room and see all these blokes being in the same boat. (C15)

The Study practitioners perceived the advantages of groups in similar terms to the members themselves; that is, as sources of support, information, learning and positive attitude:

> These are all people in the same boat just getting on with it and supporting each other to get on with it. (B5)

6.1.2 Benefits to the community

As well as benefitting their members self-help groups provide many advantages at a broader social level. Indeed a number of groups in the study defined themselves more as community groups than as self-help groups. The groups were a means of connecting local

communities; members and group leaders often being participants in numerous organisations such as tenants associations, residents' groups, school governing bodies, book, art and theatre clubs and voluntary societies. As such they were able to act as channels of information about topics, events and ideas far wider than the condition that the group addressed:

> We are part of the community and that's what we're here for is for the community, not just for any particular service users, you know, we're here to help the whole community. (C17)

In some cases groups were actually providing extensive services and facilities that would clearly enrich their local area. One group had opened two disused premises which they were now running as drop-ins and in which they offered education, play, training and respite activities as well as providing opportunities for local people to volunteer.

The benefits felt by individuals, such as better health and greater confidence, also had broader implications, as members began to take an increasingly active part in the local economy and even return to employment due to the impact of the group

> one of our members who is an American lady she'd been going for interviews she's been wanting a job for a while but with her particular problem she finds it difficult…We did say to the practice manager…'oh we all know of somebody who needs a job'...she got the job…I think we can take credit, the rest of the ladies in the group. (C9)

Members of some groups, particularly those from ethnic minority cultures, saw themselves as role models that could thus inspire greater integration and participation amongst those populations that had traditionally been reluctant to get involved in local networks. They gave members the confidence to go out and try new things:

> I mean the thought of Asian women of this age doing Salsa dancing this is unheard of and they've been made aware of health issues that perhaps they hadn't known about or hadn't thought about before and they are so much more aware of what's going on around and about in the council at the political level. (C10)

> So when we give a performance in the High Street for the public, that will actually promote our cultural, our Chinese culture to the community. (A11)

In addition, the political learning which included organisational, administrative, leadership and negotiation skills were all transferable and were being made use of to enrich, empower, inform and connect local communities:

> another one of the mums on the committee [name] – she's special needs herself and watching her, she's doing a voluntary course and she'd have never done that without the enthusiasm that the group gave her – and just watching these parents

> develop and do things is amazing – I love it – and then in turn how they help others. (C6)

From the perspective of local health and social care agencies, attendance at self-help groups could have a direct, positive impact on the community through re-engaging people, especially those within traditionally excluded populations, in health services:

> I mean virtually any time that I've gone out and given a talk I will pick up phone calls from people who have been at the talk in their sort of subsequent days sort of saying, oh you know, I really, I learned an awful lot…. We've seen people who have then re-engaged with health services. (B3)

> About 30 people came…there were people there…..in the more harder to reach category. (B8)

These groups thus appear to be fulfilling the type of role at the heart of policies such as the Big Society, that for many years have attempted to encourage local participation, community activism and empowerment and the development of strong social capital networks:

> we are here to look after the people of [City] and [County]…we've become a recognised group in the local community ….. and through that we are able to do certain things within the community which means that you know we are able to put a bit of pressure on the council put a bit of pressure on primary care trust things like that. (C7)

> just the fact that there's a group can have a positive effect on the community and it sends out a very positive message…groups create communities and some of them have quite old-fashioned community views…it creates safer communities in a way where there's groups meeting and then people coming and going and there's activity and they're connected. (A6)

6.1.3 Benefits for practitioners

Both practitioners and group members saw self-help groups as a means of consolidating and enhancing the effects of health and social care services:

> We can be a back-up to the NHS. (C18)

The idea is that people, having come through treatment, understanding what's worked for them, recognising that actually talking to somebody who's been through what they've been through or something very similar is extremely important. On the whole, practitioners' relationships with groups were perceived as mutually beneficial. One practitioner described her experience as:

> A two way process of giving and receiving information from both parties. (B3)

Service providers would clearly have a strong stake in self-help group members' being better informed about their condition, with one of the particular advantages of these groups being that knowledge could be shared on an on-going basis. This could be particularly important for conditions for which a complex range of treatments was available or which were affected by many factors, such as diet, medication and lifestyle. Similarly for those conditions where practices and treatments were developing very rapidly group meetings provided the means for both practitioners and members to keep abreast of research and changes:

> I go and obviously when I get the year's programme of events, you know, it's interesting to hear when there are speakers…where we have specialist speakers talking about the retinal eye screening programmes and things like that. So I mean it's a programme that's generally of great interest to most people anyway, so yeah, whilst I'm there as a professional… I probably get as much out of the programme as they do as well...When it's something that's maybe slightly new quite a lot of us from the hospital will go along just to keep ourselves up to date. (B3)

The information disseminated at group meetings could be particularly beneficial when it was outside the practitioner's field of expertise but covered areas that would affect patients' health and well-being more broadly:

> I do learn from them, like, the last one was about the voluntary sector and all the help that's available…and there was a very good one on benefits once so that we can have more understanding of the changing benefits system. (B1)

Practitioners not only benefitted from this sort of technical knowledge but also, through attending group meetings, were able to broaden their professional perspective by seeing patients in different settings and circumstances than was possible in their official role:

> I love doing it…especially because the job that I do, I'm very much on the telephone, so I don't do much face to face, so…once a month when I actually get to speak with people face to face, that I really enjoy. (B4)

> I enjoy doing it, you know, we see a cohort of people here in the acute setting but the bulk of people with diabetes are managed in their GP surgeries or in Type 2 clinics in the community. So it gives me an opportunity to sort of see a wider audience. (B3)

> I think you learn an awful lot from listening to people talking to each other probably more than you do if they're talking to you…I identify needs that aren't necessarily on your clinical agenda, but actually have an impact and you might be able to develop that somehow. (B5)

They were also able to use their visits to meetings to correct misinformation about medical advances or political changes:

> Somebody's read something on the internet or they'll bring in you know something out of the Daily Mail and it will be this new wonder drug and you know….I actually do feel it's my place, I do feel that it's my place, to actually say, well you know yes, but it's actually only been tried on a couple of rats in a laboratory. (B4)

The groups were seen as a channel through which health message could be disseminated to large numbers of people at once with the clear implications for efficiency that this entails. The same was true for broader types of information about welfare benefits, changes to legislation or service provision and the availability of local opportunities and amenities. Furthermore these messages were not only received by the group members, but in turn cascaded out to a far larger population:

> And these parents are representing so many more parents, if you... I mean the way I tried to sell it to the great and the good is that there's 13 support groups who are representing hundreds of families, so you are, you know, if you come to our meeting and talk to our parents, you're actually reaching a lot more parents than just the ones that are there. (B11)

Groups were also contributing to the wider dissemination of health messages through their extensive awareness activities at local hubs such as markets, town centres, libraries and carnivals. These events provided the opportunity to distribute literature from sources such as national charities or education and health services and to address the public's need for often very basic information:

> We've been to the [place name] show…it is just literature and things, and it is just amazing number of people we get come and talk…I mean I was only there for about two hours and the number of people that stood and talked, always about their condition. (C2)

These types of event also gave local practitioners the chance to meet other service providers and to improve their knowledge of the range of services in there are:.

> We started to have meetings that involved people from external agencies - [name] and Inclusion Support came along and told us what service they provided and…we actually had the main secondary school…we had the headmaster, SENCO and the head of year. (C8)

Groups were also adding to the breadth of knowledge available to health and social care services by attending and contributing to professional events:

> …they turn up now at our large CLRN conferences with their own stand, all their bumph written out, all their plans of what they're going to do. (B5)

> …we just did an event last week, the week before last….which brought together self-help groups, support groups and health interest groups together and the

> programme was really designed by a steering group of people from self-help groups, and we had 118 people there. (B8)

In addition members used their repository of knowledge and experience by acting as key contributors to Public & Patient Involvement and other consultation process, thus ensuring that professional and policy objectives promoting public engagement in service design and delivery were being fulfilled:

> …so they're actually feeding in now - when anyone comes to me needing some Patient Public Involvement then that's the sort of group that I would offer them, which is really useful. (B5)

Group members were often aware of the constraints on health services that could result in inadequate or short term provision. This was seen as a particular problem in areas such as mental health or alcoholism where patients' need for support was on-going. The groups therefore acted as a means of extending services and prolonging and consolidating their positive effects:

> There wasn't much for anybody when they were going to be discharged from treatment….nothing to support people in moving on or out there in the community. (C17)

The groups also acted as a forum for discussion about these constraints and the pressures, particularly financial, acting upon public services:

> I think there's so many different support groups for so many conditions that it would put too much weight on the NHS to provide funding. (C 18)

Through such dialogue they were helping to improve understanding of the jobs done and difficulties faced by service providers and to give members more realistic expectations. They could thus help to create more positive views about and relationships with the NHS:

> we always constantly tend to moan about the NHS but then you realise….. you actually start to appreciate some of the things that do happen on the NHS. So yes, we will constantly fight to try and change the local services because we believe that, having been patients, there's always something that can be done differently and yes, if we can, we'll fight for our local services. But it also helps us realise that actually it's not always as bad as we tend to make it. (C12)

6.1.4 Benefits of practitioner input for self-help groups

Groups described numerous ways in which input from practitioners had benefitted them. This could be in practical ways, for example through providing a venue, grants or training or in less tangible ways such as offering informal advice or the chance to build up local links and social networks:

> Yes he was fantastic – he came to meetings and to the AGM – he's given us really good advice – it was him who said we weren't applying for enough and should go for £3000 and he gave us the idea of paying for things like room hire in advance, to get the money spent. (C2)

Some groups particularly valued the technical, specialist input that practitioners could contribute:

> I'm just saying, the best information source has been from those talks that we have once a year, in particular the first one we had, because he was telling you about the future…And there was one on diet. (C16)

For others the support they received in running the group was vital. This was especially so when their health condition presented barriers against their leadership role:

> We had a coordinator…when she was the coordinator it was lovely then…Because she got more…she knew more people…And she was lovely. She used to tell us what was happening, then if I wanted to discuss where we go, she could discuss it better with them…she had a way with people. You see I'm the same as the members, I'm struggling to make them understand (C13)

Indeed some groups felt that this involvement was pivotal to their very survival:

> Without help from Self Help Nottingham we couldn't just do it all ourselves. (C9)

7. Top Tips for practitioners

Across and within the practitioners' and self-help group members' accounts a range of approaches and areas of focus were identified as important factors to consider when working with self-help groups. These factors have been identified as 'top tips' for practitioners and involve:

- Build a trusting relationship with groups
- Be clear about your role and its limits
- Help groups get a local profile and credibility
- Value different kinds of expertise and support
- Be friendly, approachable, non-judgemental and flexible
- Be positive: assess the risks and take a 'leap of faith'

Build a trusting relationship with groups

The importance of trust between practitioners and self-help groups was identified as crucial to developing good working relations. The most effective ways a practitioner might achieve this was through remaining available and ensuring requests made, and agreed to, were met and if not for groups to be kept informed:

> A lot of this is about building up trust…[they] have to have trust that you are going to do what you say you're going to do and keep them updated and respect what they do, because people are volunteers, they're giving up their time, and they already have a condition that has compromised their lifestyle to this stage where they feel they needed that amount of support. (B12)

> It's very important to make sure that groups know that we are always here for them, no matter what stage they are at, no matter what the circumstances are. (B2)

Be clear about your role and its limits

Being clear and open as to what you can offer and provide a self-help group were identified as important tenets to building trust and confidence, and are particularly pronounced if a practitioner is involved in the instigation of a group:

> Knowing what your remit is from the start, with setting up a self-help group is key. (B14)

> We have to be very clear with groups about what we can and we can't provide.... Our intention is never to lead a group along a certain path and for them to think that they're going to get a particular outcome from it, that they would not necessarily be able to achieve. (B2)

Help groups get a local profile and credibility

The importance of helping groups to develop a local profile and credibility was identified as crucial if groups wanted to have an impact and make a difference, as well as being intrinsic to securing future development:

> With the help of Self Help Nottingham we started to begin to become more involved in the community and we developed community status and now we're involved in lots of things and therefore we have become a much stronger group. (C7)

> If they knew our name from somewhere else first – 'Oh, I've heard of this lot, yes!' you know. It's all trying to get yourself a little bit of an edge… give yourself some sort of standing. (C15)

Value different kinds of expertise and support

There were differing opinions as to whether or not it was necessary for a practitioner to be fully informed and knowledgeable about the condition or issue that brought group members together:

> If you understand the fact that you don't share that issue that they come to you, you don't even need to know very much about it, what you want to do is foster a relationship between that person and other people in the group and not with you. (A7)

> Be as knowledgeable as you can...I have to learn quite a bit about the groups, as well as individual's conditions and experiences, about management styles and that sort of thing. I've always found it helpful to understand people as much as I possibly can, and that could be anything from, yeah, sort of a theory type thing or a personality type thing, or just the person you're sitting talking to, to try and sit down and talk to them, to understand what's going on for them. (B2)

However, there was broad agreement that for practitioners to work effectively with self-help groups they need to recognise and value the benefits associated with peers supporting one another and not to feel professionally undermined:

> I think that as a professional working with this I think you have to have the confidence not to be undermined by people taking some control over their own health because I always say that self help and support groups should work alongside and compliment the care you get from your GP…it's an added support. (B12)

> I think the wise professional is one who can see the potential benefit of people learning from experiential knowledge as well as professional knowledge. (A2)

Be friendly, approachable, non-judgemental and flexible

A range of interpersonal skills were identified as helpful when working with self-help groups, as many favoured a friendly, approachable, non-judgemental, flexible approach:

> …just to be approachable and friendly and to, you know…it's about listening and not judging, because people will make the choices they make, it's not up to me to judge them for those choices…these are all skills that you've got in your tool box, this is just another tool that you add to your tool box, and it's being able to switch between them, you know, if you were taking one of the screws out on that wall you'd look at it and you'd go, oh, that needs a Phillip's screwdriver or that's just a standard screwdriver, you use what you need to do the job, and you have to keep changing hats. (B3)

Be positive: assess the risks and take a 'leap of faith'

Working with self-help groups at times is likely to raise a number of issues and tensions for practitioners. It might require taking a 'leap of faith', even when initial impressions are not promising and the outcome can be surprising:

> One thing that I thought about is that notion of taking a leap of faith with people and I like the fact that we do that here … We're prepared to take a risk as long as we've looked into it and sorted out the consequences of that. (A6)

> The other little thing I've learnt is never try and pre-judge things you know when somebody that walks through the door saying 'I want to set up a group'. I think it's tempting to think well, you know, will this work?…and I've fortunately had enough times when I've been completely wrong. (A6)

8. Discussion

This section draws together some of the key issues that have been illuminated from the practitioner interviews and discusses them in relation to findings from stage one of the study. Overall the study has highlighted the complexities of ways and nuances in the relationships that practitioners can have with self-help groups. One established criteria for 'self-help groups' is that they are member–led, this definition tends to imply that practitioners are only ever 'invited guests' to groups, however the data from both groups and practitioners in stages 1 and 2 of the study suggest a more complex picture with a range of roles and activities that practitioners contribute to group development. This inevitably raises questions about ownership and control of groups. The discussion is organised under two main themes: practitioners' spectrum of involvement with groups moving on to discuss the types of roles that practitioners might take in relation to groups.

8.1 Practitioner involvement groups: issues of ownership and control

The autonomy ascribed to self-help groups in the literature (detailed in the ESTEEM Stage 1 report) was not straight-forward here. Section 6 illustrates the ambiguity and debate regarding the extent to which practitioners should get involved and the issues which they should seek to influence in self-help groups. A few practitioners questioned the distinction between autonomous and professionally-managed groups. The data suggest that not only is there a spectrum of varying group autonomy across different kinds of groups but also within the same groups at different times in their evolutionary journey. In this section we explore this idea by examining two kinds of groups where this debate was focused: newly emerging groups and minority ethnic groups. Of each, we ask:

- Who makes the decisions?
- Who runs the meetings and organises the activities?
- Who feels a sense of ownership?

All newly emerging groups were said to need more practitioner support than established groups but there was a fundamental difference between those groups instigated by practitioners (often health and social care professionals) and those instigated by people with the condition or social issue around which the group was focused. The key decision to set up a group and how early activities are organised was decided by practitioners on the one hand, and founder group members on the other. This distinction is somewhat blurred when founder members receive intensive support from practitioners, but these supporting practitioners can be welcomed or dismissed, an option not available in the professionally-instigated group. In keeping with existing literature in the field groups founded by peers develop a strong sense of ownership, whereas it may be initially unclear or undeveloped in the professionally-instigated groups.

Generally, this suggests that members of professionally-instigated groups may have much less control and ownership than those in groups instigated by their members. The ESTEEM data (stage one and two) showed how difficult it can be to shift members' mind-set from one to the other. Autonomous groups like to retain control while

professionally-managed groups like to retain their practitioner involvement: an understandable preference for stability. This simple distinction, however, falls apart where practitioners set up groups with a clear remit to be self-organising and adopt a skilful, backseat role from the start. The data suggested that not all practitioners could do this, but a few appeared to have been successful and professional instigation is not necessarily a bar to a strong sense of ownership so long as it is done with respect for the peer nature of groups and on the group's own terms. In addition, some groups were supported by Self Help Nottingham to manage the sudden withdrawal of their professional facilitator and were given transitional support to being fully peer led enabling them to achieve high levels of control.

Two of the ethnic minority groups illustrated this point to different degrees. Both the Chinese (C20) and South Asian women's (C19) well-being groups were set up by community development workers of the same ethnic backgrounds after a local needs-assessment into community support. Both groups were fairly well-established at the time of the study. The Chinese group had a committee of members who made the decisions about what to do and the South Asian group had a more ad hoc ethos of group decision-making. In the Chinese group each committee member had a role, from Treasurer to Tea-maker. In the South Asian group, a member of the group was nurtured to take on a lead role. This impression of group control and ownership is complicated by the continuing involvement (at a distance for the Chinese group) of the community development workers. In both groups most members lacked English language and literacy skills, knowledge of institutional and structural systems, funding arrangements and confidence in organisational development. They relied on support to get their meeting rooms and funding. Their decision-making relied on receiving information about the available options. Both groups might have ceased without practitioner support, although the Chinese group was being actively encouraged to become self-organising and independent.

What counts as autonomy here is unclear but the groups do not seem to fit the description of 'professionally-managed' due to the emphasis on members making the decisions, running the meetings and the Chinese particularly had a strong sense of ownership. Their support comes from within their own community, and during the study changed from professional to volunteer involvement as the practitioners continued to support the groups after being made redundant. The dichotomy between autonomous and professionally-managed groups applies where the status and power of health care practitioners sets them apart from service users. Perhaps this dichotomy has less application to self-help groups within minority ethnic communities where practitioners and group members are connected by their ethnic and cultural identity.

We have noted above that groups need different levels of support at different times, as practitioners sometimes step in to lead roles at times of difficulty. The approach of some practitioners enhance group control, while others seem less skilled, less sensitive to the issue and less likely to take that 'leap of faith' that one practitioner spoke of. For those interested in promoting group autonomy for the benefits it brings, these features of practitioner support are vitally important.

8.2 Practitioner roles

Judy Wilson (1995) argued practitioners working with self-help groups must be clear about the role they are undertaking within a group and recognise if and when this role might need to change over time. Taking and developing Judy Wilson's ideas around practitioner roles, five broad practitioner roles were identified from the ESTEEM data. These roles were partly linked or dependent upon the practitioner's job role, but contextual factors, such as the needs and developmental stage of the group, also played an important part. Recognising which role was suitable for the group and attainable for the practitioner was key. The roles are not mutually exclusive. These five broad roles were 'resource-builder', 'capacity-builder', 'facilitator', 'bridge-builder' and 'co-educator'. A summary of roles, the activities they involve and who was carrying them out can be found in Table 3.

Resource-builder

Practitioners from every sector provided practical help of different kinds. It did not demand much of their time, as it mostly involved making resources that were easily accessible to practitioners readily available to groups (see 4.2). However, from the group's perspective having practical help was often hugely beneficial, particularly when groups had limited funds.

Some practitioners within the voluntary sector helped to identify, secure and account for suitable funding. These practitioners responded to one of the greatest concerns of the groups but we noted this remained one of the most challenging kinds of support.

Capacity-builder

Capacity-building included a range of activities which usually required more of the practitioner's time, often involving working with a group or key members over an extended period. Practitioners from all sectors were involved in different ways, but essentially they were helping to develop a group's confidence and providing them with the necessary tools to aid the running of the group.

There was some variance as to how practitioners went about building capacity. In some cases it was through the delivery of formal training, whereas in other circumstances the practitioner adopted a coaching role where group members were actively involved and leading the process. A more detached approach was being a critical friend, where group members were encouraged to reflect on alternative ways of doing things, leaving the decision up to them.

Facilitator

Facilitators smoothed the groups' progress and members' participation from the time they started, sustaining them through periods of struggle or conflict, and helping them come to

a close if necessary. Again, practitioners from across the sectors helped in this way, doing different activities to fit their professional interest and expertise.

Those acting as catalysts for change identified and created opportunities throughout the lifecycle of a self-help group. Health and social care practitioners instigated or supported emerging groups, raising questions about their current and future role discussed above. Voluntary sector workers had a less complex relationship with the groups when adopting a pivotal role in their inception.

As noted above, support may be needed throughout the life cycle of a group, to ensure sustainability through periods of struggle and perhaps with coming to terms with and dealing with the need for closure. Sometimes facilitators acted as a mediator in response to deteriorating group member relationships.

A more common aspect of facilitation by health and social care practitioners involved ensuring group meetings ran smoothly. Practitioners taking such a lead role in meetings suggested the groups might be categorised as professionally-managed rather than self-help. The data showed the complexities and tensions around this distinction (see above).

Bridge-builder

Bridge-building involved a range of activities from simply putting people, groups and agencies in touch with each other to advocating, representing and increasing understanding. It was especially useful in the NHS where groups sometimes struggled to be heard and respected.

Groups that were starting out or floundering in some way benefited greatly when a practitioner was able to link them to relevant networks, organisations, individuals and other self-help groups, as it often strengthened their community status. Through the development of these links and networks groups were usually in a more favourable position to promote their voice. The role of a link and network initiator was not just about linking and networking groups, but it also could involve linking and networking wider organisations across the community to groups. Sometimes bridge-building involved helping people from different sectors to understand each other.

Co-educator

Practitioners, especially those from health, took part in a wide range of educational and learning activities described earlier. The learning involved depended to a large extent on how they saw their position in relation to the groups. Some guest speakers to groups saw themselves as an expert, presenting their expertise as speaker or informant, while other practitioners linked to groups tended to feel that they had as much to learn as to give. Some spoke of ‘co-production’ and the mutual learning provided a solid foundation for this approach to service development.

A wide range of practitioners and others helped groups to extend their awareness within their local communities, by opening up facilities and opportunities for these activities. Practitioners within statutory services and community development agencies were most likely to prompt groups about becoming more inclusive and diverse, a difficult topic presented above. The different roles practitioners adopted and their varying effectiveness determined who benefited from their activities.

Table 3: Practitioner roles and activities

Broad role	Activities	Location of practitioner[3]	Evidence-base
Resource-builder	Providing practical help *(with venues, facilities etc.)* Funding advice, assistance, coaching and training Monitoring and evaluation advice, coaching and training	Health and social care practitioners provided practical help. Voluntary sector agencies carried out all these roles.	4.2 5.2
Capacity-builder	Coaching (*supporting group coordination)* Training *(formal and informal teaching)* 'Critical friend' *(suggesting alternative ways of working)* Confidence-building *(encouraging and affirming)*	Health and social care practitioners helped to build confidence and could be critical friends. Voluntary sector agencies carried out all these roles.	4.2 4.3
Facilitator	Sparking/catalyst for change *(from start to winding up)* Mediation *(smoothing group dynamics)* Sustaining group *(leading coordination; helping in a crisis)* Enhancing member participation *(taking lead at meetings)*	Health and social care practitioners took on all these roles, especially starting up groups and facilitating meetings. Voluntary sector agencies rarely facilitated meetings.	4.3 5.3
Bridge-builder	Networking and linking *(putting groups/people in touch)* Advocating *(speaking up for groups)* Promoting group voice and influence *(increasing opportunities for groups to get their views heard)* Improving inter-sector understanding and communication Increasing access to the groups *(increasing signposting by clinicians and others)* Representing *(speaking on groups behalf at formal meetings)*	Health and social care practitioners helped groups to build relationships across the NHS, gain credibility, contribute to service development and become a resource for clinicians. Voluntary sector agencies helped groups to build links and profile in the community, and sometimes represented their views at various formal meetings.	4.5 5.2
Co-educator	Informing *(presenting expert information at meetings)* Co-learning *(increasing personal /professional learning)* Awareness-raising *(raising awareness within community)* Encouraging inclusion and diversity	This role particularly applied to health and social care practitioners. It enhanced group effectiveness. Co-learning potentially helped to improve services and provided a foundation for co-production.	4.4 5.2

[3] Locations of practitioners included health and social care (statutory-funded) posts; voluntary sector, which mainly refers to Council of Voluntary Services (CVS) and national charity organisations.

8.3 Issues that impact on the role and involvement of practitioners with self-help groups.

Threaded through the narrative in this report a number of issues were raised that potentially impact on the practitioners' role and level of involvement in self-help groups. These pertain not only to the dynamic between the practitioner and group and the internal dynamics of groups but also to the wider context in which groups are now operating.

Leadership and membership issues

It appears that the idealised view of self-help groups as operating collectively and democratically may be too simple and needs to take into account contextual factors including the character of the leader and the reliability, capability and wishes of the membership. This presents a challenge to practitioners who acknowledged that the 'power' behind many groups derived from the leader and who felt that their role was both to 'support the leaders' but also to encourage the membership to 'run it for themselves.' Too prescriptive an approach to leadership or members' roles may thus risk undermining the balance that is appropriate to an individual group's circumstances. And the findings from stages 1 and 2 of the study show that groups can run very successfully with a strong individual leader and very little input from the broader membership.

Facilitation issues

Most of the practitioners interviewed showed awareness of the importance of self-help groups' ethos of being peer led and offering reciprocal help. However, the picture had nuances and respondents from voluntary sector agencies, whilst still referring to a group's being 'run by and for its members' as essential to its definition as a self-help group, were in fact working with and supporting groups displaying a range of leadership models including professional facilitation, volunteer facilitation, co-production, hybridity or extensive practical support. The distinction appeared to be more subtle than the actual status of the leader and depended on the attitude of the professional or agency involved. The way that practitioners talk about professional leadership or facilitation of groups appears however to be important and can have practical repercussions. Differences in terminology and emphasis amongst the ESTEEM practitioners had occasionally resulted in tensions and poor links and communications between agencies who should have been working in partnership.

A few practitioners expressed reservations about the potential for some types of groups to be fully member led due to the particular issues the groups were facing – in the main these reservations were about mental health groups and involved issues about undue stress on co-ordinators or safeguarding issues. On one level these are understandable concerns and reflective of practitioners' duty of care and maybe own 'need' to balance autonomy and protection of the people and groups they work with. On the other hand these views appear somewhat surprising in light of the extensive history of successful user-led mental health groups and organisations in the ESTEEM sample, the UK and internationally (Munn-Giddings et al 2009, Wallcraft with Read & Sweeney, 2003).

The role of volunteers

A number of practitioners had been responsible for introducing volunteers into self-help groups. This raises interesting questions regarding the evolving definition of self-help as it could be argued that the use of volunteers discourages a self-help ethos based on the experience of a shared condition and the consequent perception of member ownership of the group. In addition it could risk the development of hierarchy within the group and lead to a lack of incentive to build members' own skills and capacity. Supporters of a role for volunteers may however feel that without them some groups would not be viable, or that the strain on leaders would be too great as indeed appeared to be that case with at least one of the study groups. The ESTEEM practitioners' views on volunteers suggest that for some their perception of self-help has moved away from traditional ideas towards more flexible, hybrid models that incorporate a wider range of participant. Indeed the only real objection to the use of volunteers was justified not in ethical terms, but rather by their limited reliability and commitment compared to paid professionals.

8.4 Conclusion

The broad and diverse range of practitioners that contributed to this study highlight the varied ways practitioners are working with self-help groups. These collaborative relationships were partly linked to the practitioner's job role, but contextual factors, such as the needs of the group, also played an important role. The practitioner and group member accounts illustrate the range of benefits associated through collaborative partnership working, such as the facilitation of mutual learning and networking opportunities. Similarly distinct areas of tensions and challenges were raised, for example around facilitation that had the potential to foster misunderstanding and frustration. Recognising the role practitioners can adopt, which is suitable for the group and attainable for the practitioner was often key to avoiding and managing these tensions.

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